30645

NATIONAL LIBRARY
OTTAWA

CANADA

BIBLIOTHÈQUE NATIONALE
OTTAWA

NAME OF AUTHOR. MARGARET PAMELA CHURCHILL

TITLE OF THESIS. RENAL FAILURE: A STUDY OF PATIENT CAREERS

UNIVERSITY... ALBERTA

DEGREE FOR WHICH THESIS WAS PRESENTED.. M.A.

YEAR THIS DEGREE GRANTED. 1976

Permission is hereby granted to THE NATIONAL LIBRARY OF CANADA to microfilm this thesis and to lend or sell copies of the film.

The author reserves other publication rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

(Signed) M. Pamela Churchill

PERMANENT ADDRESS:

Rr. 1414
60 Parana Linkway
Don Mills, Ont.

DATED... June 23 1976

NL-91 (10-68)

INFORMATION TO USERS

THIS DISSERTATION HAS BEEN MICROFILMED EXACTLY AS RECEIVED

This copy was produced from a microfiche copy of the original document. The quality of the copy is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

PLEASE NOTE: Some pages may have indistinct print. Filmed as received.

Canadian Theses Division
Cataloguing Branch
National Library of Canada
Ottawa, Canada K1A ON4

AVIS AUX USAGERS

LA THESE A ETE MICROFILMEE TELLE QUE NOUS L'AVONS RECUE

Cette copie a été faite à partir d'une microfiche du document original. La qualité de la copie dépend grandement de la qualité de la thèse soumise pour le microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

NOTA BENE: La qualité d'impression de certaines pages peut laisser à désirer. Microfilmee telle que nous l'avons reçue.

Division des thèses canadiennes
Direction du catalogage
Bibliothèque nationale du Canada
Ottawa, Canada K1A ON4

THE UNIVERSITY OF ALBERTA

RENAL FAILURE: A SOCIOLOGICAL STUDY OF PATIENT CAREERS

by

© MARGARET PAMELA CHURCHILL

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE

OF MASTER OF ARTS

DEPARTMENT OF SOCIOLOGY

EDMONTON ALBERTA

FALL, 1976

THE UNIVERSITY OF ALBERTA
FACULTY OF GRADUATE STUDIES AND RESEARCH

The Undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled Renal Failure: A Sociological Study of Patient Careers submitted by Margaret Pamela Churchill in partial fulfillment of the requirements for the degree of Master of Arts.

W. E. Nowasky
.....
Supervisor

.....

.....

Date 0ct 19/76

ABSTRACT

The research upon which this study is based was conducted in one renal unit in Western Canada in the spring of 1973. This is an exploratory study of renal failure in which three treatment modalities - hospital dialysis, home dialysis, and kidney transplantation are conceptualized as patient careers. The findings suggest that there are differences between the three treatment groups and that these are amendable to analysis from a career perspective.

Staff and patients alike seemed to view each modality as a distinct career, and the core characteristics of each treatment program centered on the sick role which it implied. Hospital dialysis, for example, was seen as an illness modality; home dialysis represented rehabilitation, and transplantation was regarded as a recovery modality. Each career seemed to have distinct goals and norms.

Although the process by which patients chose (or were selected for) the career possibilities was somewhat complex, and not always determined by choice alone, patients did have career preferences. Most wanted a transplant - but some were clearly prepared to wait until the odds for a successful transplant were better, while others were eager to have a transplant as quickly as possible. Social class appeared to be an important characteristic in distinguishing between the two groups. Time, however, generally had a "wearing down" effect upon the patient's reluctance to be transplanted.

Hospital and home dialysis were generally regarded as waiting modalities. Sometimes convenience seemed to be the deciding factor - but, here too, there were elements of preference. Some patients appeared to welcome the secondary gains associated with an illness modality, while others clearly eschewed illness and prefered to be rehabilitated.

The findings also suggest that we should be concerned about the consequences of career choice. That is, patients may be better suited for some careers than for others. If this is so, then further study from the career perspective may lead to practical suggestions for selection criteria. It may also mean that the ramifications of treatment programs are more important than the psychological response to impaired renal function.

The staff at the renal unit under study stated that they had difficulty selecting patients for the treatment alternatives. Further research which focuses on treatment programs may thus be of practical value to those who treat and care for renal patients. The career perspective is promising but it needs to be refined and subjected to more rigorous study. The theoretical implications of this research also suggest revitalization in several areas of sociological theory including sick roles, rehabilitation, and professionalization.

ACKNOWLEDGMENTS

I am indebted to many people who have assisted me with this work. Since all of them cannot be mentioned here, I will single out those whose efforts were particularly invaluable. My thanks to the administrative staff at the University of Alberta Hospital for allowing me to do the research there. Special thanks to Dr. A. Ulan, then Chief Renal Physician, who was particularly helpful in opening the doors of the renal areas to me, and to Daisy Perry, R.N., who gave so freely of her time during the research period. I am also indebted to the patients who took me into their confidence and shared their experiences, their hopes, their dreams, and their fears. But, above all, thanks to Professor William Novasky, of the Sociology Department at the University of Alberta, who always epitomized what is expected of a teacher. Most of what I know about sociology came from him. Many can impart knowledge; he endeavoured to help me to develop a sociological view of knowledge. He demonstrated considerable patience during my slow periods, and sometimes wisely allowed me to make my own mistakes. He was often critical, but always constructive. When praise was deserved, he gave it generously. And when it came, it was doubly sweet because it had to be earned.

TABLE OF CONTENTS

CHAPTER		PAGE
I.	INTRODUCTION	1
	A. The Problem	1
	B. Renal Disease and Treatment Modalities	3
	C. Summary	11
II.	LITERATURE REVIEW	12
	A. The Moral and Ethical Issues in Dialysis and Transplantation	12
	B. Professionalism and Professionalization	16
	C. The Psychosocial Aspects of Renal Disease	25
	D. Dialysis and Transplantation as Sick Roles	31
	E. Dialysis and Transplantation as Patient Careers	36
	F. Summary	40
III.	THE STUDY: DESIGN AND DATA COLLECTION	41
IV.	THE FINDINGS	47
	A. Introduction	47
	B. The Onset of Renal Disease	49
	C. From Diagnosis to Failure: The Waiting Period	50
	D. The Anticipatory Stage	52
	E. The First Dialysis Experience	53
	F. Adjusting to Dialysis	55
	G. Changing Courses	57
	H. The Treatment Treadmill	58
	I. Treatment Preferences	58

J. Some Consequences of Renal Disease and Treatment 63

(i) The Decision to Marry
(ii) Residence
(iii) Occupational Choice
(iv) Employment Status
(v) Social Life
(vi) Patients' Concept of Themselves as Sick or Not Sick

K. Career Decisions 75

V. DISCUSSION 79

A. Relevance of a Career Perspective to Renal Disease in General 79

B. Relevance of a Career Typology to Each Renal Disease Treatment Modality 91

(i) Hospital Dialysis
(ii) Home Dialysis
(iii) Transplantation

C. Conclusions 102

D. Further Areas of Research 107

BIBLIOGRAPHY 113

APPENDICES

LIST OF TABLES

TABLE	Description	PAGE
I	Treatment Preference by Current Modality	59
II	Educational Attainment by Treatment Modality	66
III	Status of Membership in the Kidney Patients' Association by Treatment Modality	70
IV	Patients' Concept of Themselves as Sick or Not Sick by Treatment Modality	73

LIST OF FIGURES

FIGURE		PAGE
I	Trajectories of Renal Patients	38

Chapter I

INTRODUCTION

A. The Problem

This is a sociological study of renal disease. More specifically, this is a study about the ramifications of a new technology - in this instance dialysis and transplantation - which can prolong the lives of those suffering from chronic renal failure. These patients are in a rather unique situation and this research attempts to outline the patient careers which they pursue as a consequence of their therapy.

Until recently the loss of kidney function, or "renal failure" as it is more correctly called, spelled certain death. For a number of years there had been talk in medical circles about the possibility of maintaining these patients by either dialysis[1] or transplantation. However, little attempt was made to treat patients with chronic renal failure until both procedures were feasible. The first patients were accepted approximately fifteen years ago. Treatment was expensive and early results were disappointing. Within the past five years, however, dialysis and

---

[1] Dialysis may be accomplished in two ways: via the peritoneum or the blood stream. Hemodialysis refers to a procedure whereby the patient's arterial blood supply is diverted through a machine which, by osmosis, filtration and diffusion, removes the impurities or wastes in much the same way as the kidneys would normally do. The blood leaves the machine and is returned to the patient by a venous route. This was the preferred method at the time of the study. Peritoneal dialysis was used only as a stop gap measure until hemodialysis or transplantation could be done - or as a dialyzing technique for a small number of patients who were not good candidates for hemodialysis. More recently, however, peritoneal dialysis is enjoying renewed popularity. See: Open Forum: peritoneal dialysis. J. Ren. Tech., 2(4): 10-17; 1973.

transplantation have become more regularized and treatment centres more numerous. Today most patients with renal failure can expect to be offered a choice of treatment methods.

The choice is often only theoretical. In actual practice the choice is not always the patient's to make. Some treatment centres offer only dialysis or transplantation. Others offer both - and even a range of dialysis programs[2] but a variety of circumstances, including medical considerations, may dictate which therapy is offered to an individual patient.

Research data for this study were obtained from a university-affiliated hospital in Alberta. During the exploratory stages of data gathering the staff of the renal unit expressed concern about the implications of treatment methods and indicated that some patients were better suited to certain treatment situations. But just what characteristics determined suitability was not clear at all.

Since this centre offered three treatment choices: hospital and home based dialysis, and transplantation; it provided a rich environment for comparing treatment programs and developing some understanding of what happens to patients as they pursue the various renal careers.

The literature on renal failure, dialysis and transplantation offered little indication about how patients selected, and adapted to, these treatment modalities. This question could be explored from a number of sociological avenues. The career typology was chosen because it offered

---

[2] Initially dialysis, by either route, took place in the hospital. In the last few years there has been a distinct move to home dialysis and limited care centres. The latter are usually located outside of the hospital but employ some staff members who are available to assist patients in providing much of their own care.

a sound way to acquire basic sociological knowledge on what happens to patients with chronic renal failure. This approach, in turn, may enhance our understanding of patient behaviour which, despite a flurry of research, is still largely unknown. If it is successful the findings may be of both practical and theoretical value.

B. Renal Disease and Treatment Modalities

Some background information on renal disease and treatment technology will enhance our appreciation of the problem under study. Chronic failure, which is the focus of this particular study, follows the deterioration of the kidneys. This kind of failure usually develops insidiously over a number of years. The cause varies. Sometimes it is due to recurrent kidney infections. Sometimes it is due to degenerative diseases, such as polycystic kidney disease, which often have a genetic basis.[3] Sometimes the patient knows that he is headed for failure; sometimes he does not. Although shut-down usually brews for years the onset may occur suddenly before it was expected. Regardless of the cause, or the timing of the onset, renal failure means certain death unless the patient is treated by long-term dialysis or transplantation.

Each treatment method has drawbacks. Regardless of the type or the

---

3 At least five of the patients under treatment in this centre had kidney disease of genetic origin and had watched other family members develop failure, undergo treatment and die. This kind of rehearsal must have some effect on the patient's response to his own disease.

routine,[4] dialysis is a treatment and not a cure. It is an expensive treatment that usually costs in excess of ten thousand dollars per patient per year, and it interferes with the patient's normal life. Not only must the patient take time out (up to twenty-four hours a week) for the procedure, but he must also restrict his diet - and particularly his fluid intake. Even highly motivated patients must find dialysis, and the routine it imposes, wearisome. Long-term use of the artificial kidney machine is also revealing its inadequacy as a kidney substitute. Some senior patients are developing bone disease and blindness. Although newer techniques now necessitate fewer blood transfusions, when transfusions are necessary they can increase sensitivity and thus potentiate rejection if a transplant is done.

Renal transplantation is an alternative treatment. Actually it is more than a treatment - it is an attempt at a cure. Unfortunately, it is not always successful. Transplanted patients constantly live with the threat of rejection of their new kidney, and must remain under medical supervision. In the early days patients who had been transplanted generally lived only a few days. A world-wide registry, which was established in 1963 in order to accumulate data on renal transplantation in man, reported that as of 1968, 1,187 patients had been transplanted in sixty three institutions located in nineteen countries. But, as of 1968, 949

---

[4] In the early days dialysis was usually offered once a week. At the time that this research took place, it was generally agreed that patients felt better, and responded more favourably, if they were dialyzed about three times a week. Again, there is some new thinking on this matter and at least one centre is moving toward shorter and less frequent dialysis in order to be able to accomodate more patients. See: Barbara Vincenzo and Jacqueline Mastrangelo, 4 hour dialysis: socio-economic aspects. J. Ren. Tech., 3 (2): 34-40; 1974.

of these patients were dead.[5] Dossetor (1967) says that only 40 to 65% of transplanted patients can expect to be alive at the end of one year. Of these 80% can expect to be alive at the end of two years. Beyond that the future is unknown. Repeat transplants are becoming more common. In fact, some patients have received a third transplant. It should also be pointed out, however, that once a transplant fails, only 25% of the patients can successfully return to dialysis. This means they must be quickly transplanted again - which is not usually possible - or they will die.

The failure rate associated with transplantation is a result of problems associated with getting the body to accept a foreign organ. Despite considerable research the rejection process is not well understood.[6] It is known, however, that success is more likely with a good match. One physician equated the odds for a successful transplant in this way. As of 1967 65% of the recipients of a blood matched kidney could expect to be alive at the end of one year. For randomly matched cadaver organs the figure is 40% (Dossetor, 1967). That being so, perhaps living donors should be used in preference to cadavers. But living donors, and particularly those who are well matched, are not always available. In addition there is slight, though not insignificant, risk to living donors and

---

5 These data and an assessment of transplantation can be found in Joseph Murray and Benjamin Barnes, The world wide status of kidney transplantation. Human Transplantation, edited by F. Rapaport and J. Dausett. (New York: Grune and Stratton, 1968), 15-60.

6 For a simplified explanation of what is known about the complex rejection process see J.B. Dossetor, Present status of renal transplantation. Canad. Nurse, 63 (10): 32-34; 1967.

this is one reason why some centres prefer cadaver kidneys.[7]

In addition to these risks more recent developments have also shown that immuno-suppressive therapy is not without its disadvantages. These range from the "moon face" long associated with steroids - to the increased risk of malignancies among patients on this kind of therapy.[8]

Current efforts are striving to make both dialysis and transplantation both successful. Research associated with transplantation is attempting to improve upon the parameters of a good match and the safety of suppressive therapy. Nevertheless, tissue-typing remains an inexact science and there are reports of good responses following a poor match and vice-versa (Fox and Swazey, 1974). In addition the list of risks associated with suppressive therapy continues to grow.

Because dialysis still seems a safer treatment than transplantation a number of innovations are being tried in order to reduce costs and also make long term dialysis more palatable for patients. Social workers and psychiatrists are often attached to renal units in order to help patients and families to cope with the stress of treatment. Home care pro-

---

7 Hamburger and Crosnier state that the immediate operative risk for donors is 0.05 per cent. The long term risk of losing the one good kidney is 0.007 per cent. The latter is said to be roughly equivalent to the risk incurred in driving a car for 16 miles every working day. See: Jean Hamburger and Jean Crosnier, Moral and ethical problems in transplantation. Human Transplantation, edited by F. Rapaport and J. Dausett. (New York: Grune and Stratton, 1968), 37-41.

8 Fox discusses this and other aspects of drug therapy. Renee C. Fox, "A sociological perspective on organ transplantation and hemodialysis." Ann. N.Y. Acad. Sci., 69: 406-428; 1970.

grams[9] and limited care centres reduce the financial outlay of the hospital and help the patient to normalize his life.

The advantages of home care are obvious. The patient can sleep during his run and spends less of his time travelling to and from the hospital. His self-respect is often revitalized when he is able to assume responsibility for much of his own treatment. But home care can also place a tremendous burden upon the patient's family - most especially the one member who is selected to be the partner. This is less true than it once was, for early programs emphasized training the partner, rather than the patient, and this made the partner - who was usually the spouse - into a substitute doctor. Now most programs primarily train the patient and the partner is more of an assistant. This newer approach relieves the partner of some of the onerous responsibility for the patient's life.[10]

The limited care dialysis centre[11] is a more recent innovation. It is a sort of half-way house between hospital and home dialysis and, as such, has some of the advantages of both approaches. Usually such a centre is set up in a large house. It is staffed by some professionally trained persons, frequently a nurse and a technician. Patients dialyze

---

9 Rae and Craig provide a good discussion of home dialysis and compare the costs to those incurred in hospital-centered programs. See Angus Rae and Pauline Craig, Home Dialysis: . Its costs and problems. C.M.A.J., 106: 1305-1318; 1972.

Sampson provides some insights into the selection and training of patients for a home care program. Tom F. Sampson, Home Training: transversing the maze. J. Ren. Tech., 3 (3): 20-28; 1974.

10 For a discussion of the problems of spouses see: Philip Shambough and Stanley Kanler, Spouses under stress: group meetings with spouses of patients on hemodialysis. Amer. J. Psych., 125: 928-936; 1969.

11 This type of program is discussed by Pittard. See: Joanne Pittard, Self care dialysis. J. Ren. Tech., 3 (3): 18-47; 1974.

themselves as they would at home, but the staff members are available to act as partners and to handle any emergencies that may arise. The chief drawback to such centres, and one reason why the unit under study was having difficulty persuading hospital administration to establish one, is that the staff in such centres do not have the protection (and back up facilities) which they would have in a hospital.

The debate[12] on choice of treatment - dialysis or transplantation, and how to help the patient to cope with it, is more than academic. The staff at the unit under study spent considerable time discussing this topic. A brief review of the history of this unit suggests that initially dialysis itself was seen as a great break-through. In a very short period of time it came to be viewed as a stop-gap measure to be used only until a transplant could be done. Despite early disappointments from 1967 to 1971, transplantation continued in earnest until 1972 when it declined sharply.[13] Then the staff reverted to dialysis. An attempt was made to use counselling and psychiatric practices in order to make hospital dialysis more bearable. This too proved disappointing. Home care was the next possible

---

12 For an account in which several renal physicians reflect on the past and speculate about the future see: Open Forum: a twenty year perspective. J. Ren. Tech., 3 (3): 36-39; 1974.

13 Although survival statistics were not made available to the researcher, a log kept by the nurses states that of the four patients transplanted in 1967, three died within two months and the fourth by one year. Three patients were transplanted in 1968 and all died although two lived about one year. In 1969 eight patients were transplanted and, of these four were still alive as of 1973. Of the ten transplanted in 1970, four were still alive. 1971 was the boom year - seventeen transplants were done and five patients survived - but three survived without their transplanted kidneys. Thirteen transplants were done in 1972 and eight patients survived - but only three kept their kidneys. In the first five months of 1973 the log shows only three transplants. One of these patients lost his kidney within 3 months and the other two were transplanted just shortly before the study was completed.

panacea and for a while great effort was expended to divert patients to this treatment modality. About the time of the study it became increasingly obvious that home care could not work for everybody and the staff began to seriously consider the development of a self-care centre.

As a result of this confusion about treatment programs this research took place at what was probably a low point in the history of this particular unit. Hospital administration evidenced little interest in the treatment of renal patients. Facilities for their care were scattered throughout the hospital and an old pavilion. Renal physicians had divergent interests - one was devoted to research, a second emphasized preventative programs, and the third left towards the end of the study to pursue his goal of providing an organized treatment program. Some members of the nursing staff lamented that the patients did not get better and therefore their work didn't seem to get results. The rewards which nurses generally associate with their work were simply not available in this setting. As a result conventional wisdom dictated that nurses should not remain in the renal area for more than two years. Although not all nurses agreed, and some found new avenues of satisfaction, all agreed that renal nursing is emotionally exhausting. The patients and their families also seemed discouraged. Some felt, and at least two staff members agreed,[14] that the death rate among patients in both the dialysis and transplantation programs was "too high" and that in some instances

---

[14] In one instance one of the physicians remarked, "All of this talk about transplantation is crazy. Our two-year success rate is less than fifty percent." On another occasion a nurse commented that the unit seemed to be losing more of the dialysis patients than it should. When asked why this might be so she said, "Well, these patients need strict medical supervision and when the doctors let up they tend to give up and die." Field Notes May and June, 1973.

it was due to the patients giving up and even, with varying degrees of intent, committing suicide.

Some aspects of these problems may have been idiosyncratic - that is, they may have been peculiar to the unit under study. There is evidence to suggest, however, that the unit was not alone in its dilemma. Fox and Swazey (1974) cite similar situations elsewhere and even make reference to an informal moritorium on transplantation. An official of Statistics Canada confided that one of the unspoken reasons for establishing the Canadian Dialysis Register was to obtain some "cost-benefit" data on dialysis. Survival statistics and cost estimates alone should not determine if treatment for renal failure is worthwhile. We need to know more about how the patient views his experiences - and hence if his lot can be improved by selecting the appropriate treatment modality or by offering "support". This study does not, however, propose to answer the question of how selection techniques and support measures might be employed - rather it is restricted to describing what happens to renal patients. As the literature review will later indicate our knowledge of renal patients is scanty and before we can debate what ought to be, we need to analyze and understand what is presently happening.

The decision to focus this study on treatment programs is deliberate. It is based on a premise, drawn from the literature review, that further study on the psychological response to kidney impairment will be of little value and that we should look instead at the consequence of the treatment program itself.

The career perspective was selected as the method of analysis because it directs our attention to the shared experiences of all renal patients, and those which are associated with each treatment modality. Roth (1963),

who pioneered the use of the concept of patient careers in his study of tubercular patients, examined the development of goals and timetable norms. Despite the fact that his analysis seemed fruitful, little attempt has been made to use this concept in the analysis of other types of illness situations. In a sense, then, we are testing the approach as well as studying what it reveals about renal patients.

C. Summary

In summary, renal failure is a fatal condition which can be treated, with varying degrees of success, by either dialysis or transplantation. Each treatment program has advantages and disadvantages. Current thinking suggests that some of the disadvantages can be avoided, or at least minimized, if patients can be placed in the program most suitable for them. Projects such as this one which describe what presently happens may generate insights into the characteristics which determine suitability. At the practical level knowledge of this sort may lead to improvements in the selection process, and at the theoretical level it may enrich our understanding of patient behaviour.

The literature review in the following chapter will outline some of the approaches used in previous research and how these have added to our present knowledge of renal failure. This should help us to understand the objectives and design of this particular project which will then be discussed in greater detail in chapter III. The findings will be presented in chapter IV. Chapter V, the final chapter, will discuss some of the implications of these findings as well as questions for future study.

Chapter II

LITERATURE REVIEW

The preceding chapter hints that there are a number of avenues which social scientists might pursue in examining the implications of dialysis and transplantation. Although our interest is primarily in those which pertain to the psychosocial aspects of the disease, we can strengthen our appreciation of the many problems associated with the treatment of renal failure by reviewing what has been accomplished in various areas.

A. The Moral and Ethical Issues In Dialysis and Transplantation

The moral and ethical issues raised by dialysis and transplantation afford one of the most obvious sociological perspectives on renal failure. It is almost impossible to discuss the treatment of chronic renal failure without touching on some aspect of the moral problems involved. These issues arise from two features of the treatment: (1) it is still largely experimental, and (2) it is expensive.

The experimental nature of the treatment gives rise to a number of questions of which "patient consent" is the most fundamental. As Schreiner and Maher (1965) point out, the patient may be too ill to appreciate the ramifications of selecting dialysis or transplantation - or no treatment at all. We can be just as skeptical of the family's ability to make a purely rational decision. When transplantation is considered Moore (1969) doubts that "informed consent" is ever really possible. As he says:

> When we move ... to such desperate measures as kidney or liver transplantation for fatal disease, it is evident that the hopes and the inborn optimism of youthful science combine to push the patient forward (p. 511).

Although Moore limits his concern to the recipient and his family - what about informed consent with respect to the donor and his family? When a cadaver kidney is to be used the donor is usually unaware of his role and the question of consent falls to his family. Some families have reported that tremendous pressure was placed upon them to consent to donating organs for transplant. In some instances the donor is kept alive, by artificial means, until the family is persuaded. In other instances the family is asked to refuse such life-saving devices so that the donor's organs don't have a chance to deteriorate.

Examples such as this are resulting in a re-evaluation of medical ethics and, in particular, to new medical-legal definitions of death. Institutions are becoming more aware of the need to implement safeguards to protect potential donors and their families from a overly zealous quest for kidneys and other organs.

When a living donor is considered he is usually drawn from the patient's relatives and this means that one family unit is faced with the pressures associated with both giving and receiving. Mauss' (1954) insightful treatise into the psychology of gifts should sensitize us to the possible repercussions. According to him a basic tenet of human psychology dictates that gifts are to be repaid, and thus the act of giving initiates a network of social exchange. Mauss' theoretical postulations are confirmed by Crammond's (1967) study of transplantation with living donors which led him to conclude that, as a consequence of transplantation, a significant change occurred in the relationship between the donor and the recipient.

As Fox and Swazey (1974) point out, it is important to note that the best tissue match is not always coincidental with the most psycho-

logically appropriate donor. This is particularly true when the patient is married. For psychological and social reasons, spouses would usually be best prepared to become donors. Genetics, however, favour parents and siblings as the best tissue match.

Sometimes there are strong psychological and social reasons for refusing to allow a suitably matched relative to donate. Conversely, sometimes a highly motivated donor is permitted to donate an organ even though the tissue-match is less than ideal. Fox and Swazey (1974) note that when psychological reasons determine whether a donor is accepted or rejected, the reason is never divulged and will not be written into any records.

Perhaps renal physicians recognize the impact which transplantation may have upon the family unit. Sometimes structural changes occur. Fox and Swazey (1974), for example, cite an instance in which a male patient spent his convalescent period with his maiden sister, who was the donor, rather than with his wife and children. Unfortunately, this patient died without ever returning home to his family.

Although this kind of response may be extreme, transplantation probably creates a strong psychological bond between donor and recipient. Often the donor feels that the recipient is a part of him and, while the recipient lives, the donor may feel that he has some rights over the patient's life.

Crammond (1967) tells of one woman who became very upset when her brother, who had received a kidney from her, appeared to neglect medication advice. To her it appeared that he was squandering her gift. Her concern, in turn, was translated into nagging which made his life unbearable. Fox and Swazey (1974) cite other case histories in which

the donor was devastated when the transplant failed.[15]

While ethical problems are more pronounced with respect to transplantation, and the cost factor is more prominent with respect to dialysis, dialysis can also generate ethical problems. For instance, once a patient enters a dialysis program, can he be withdrawn if he - or his family - feels that treatment is no longer warranted? The complexities of this particular situation are illustrated by an incident described by Hamburger and Crosnier in which the physician ignored a woman's pleas to have dialysis stopped. Later she said, "Don't listen to me, that's my uremia talking, not me. I want to stay on the program" (Grune and Stratton, 1968: 39).

Cost is an ethical as well as financial problem. Because dialysis may cost in excess of ten thousand dollars each year per patient, it is beyond the financial grasp of most individuals. Consequently many patients compete for acceptance into subsidized programs. This is particularly true of countries in which the public sector is not heavily committed to health care as a basic right.

Although overt screening is not as common as it once was[16] Schreiner and Maher (1965) comment that, when screening exists, it generates yet another host of thorny questions such as:

---

15 An example of this was also noted during the course of this research when a twelve year old boy received a kidney from his father. The kidney was rejected and the child had to return to dialysis. Unfortunately he also suffered brain damage in the critical post-operative period. According to the staff the father seemed to feel very guilty about the unsuccessful transplant and, from that point on, he withdrew from the illness situation and left his wife with the responsibility of caring for their son. Field Notes, May and June, 1973.

16 For a current discussion on screening see: R. Fox and J. Swazey, Courage to Fail, (Chicago, Illinois: the University of Chicago Press, 1974).

(1) What criteria should be used? Should medical criteria alone be used - or should social, psychological, and economic factors be considered?

(2) Who should set the criteria?

(3) Should social factors be dependent upon the patient's contribution to society - or the burden he will leave if he dies?

(4) Who should do the screening - medical or lay people?

The problems inherent in screening can be avoided by providing universal access to treatment. This however, makes public funding imperative and thus raises another ethical problem - namely, priorities for the health care dollar. As Fox (1970) says, the vast sums of money spent to prolong the lives of a small number of chronically ill patients could probably be better spent providing basic health care to a large number of people.

Regardless of where the funds come from there is a very real possibility that renal patients are aware that they are an economic burden to the community. If such is the case it must surely intensify the stress of treatment situations.

B. Professionalism and Professionalization

The technology involved in the treatment of renal failure is still in its infancy - or at best not far behind. It is therefore not surprising that there is a certain degree of instability in the units charged with applying this technology to human patients - and within the professions who apply it.

When this research took place there was little discussion in the

literature of professionalization within renal units. As is the case in most new endeavours there was talk about the need for an "interdisciplinarian team approach" to the care of renal patients (Whipple, 1972). There was even more discussion about the role that various professions can fill. Psychiatrists were particularly vocal about their value to renal units (Crammond, Knight and Lawrence, 1966; Kemph, 1967; Abram, 1968; Tuckman, 1969; and Taylor, 1972). Social workers too, felt that they had something special to offer (Hickey, 1972; Whatley, 1972; Cain, 1973; Goldmeir, 1973). For the most part these professions are simply claiming that renal patients need their particular expertise.

While psychiatrists and social workers are simply striving to ensure that their traditional skills are used in renal units, there were beginning signs that other professional groups seemed to be using these areas as a locus for professional change. The most notable examples here are nurses and renal technicians.

Although the medical management of dialysis patients is supervised by physicians, a great deal of responsibility usually falls to the nursing staff.[17] Nurses hook patients up to the machines, observe them while dialysis is in progress and unhook them when it is over. They exercise a fairly wide degree of discretion in handling emergencies, and in altering the patients' routine if unusual events arise. Emergencies are of two types: the machines may fail and thus set off warning buzzers, or the patient may react adversely to some aspect of the dialysis procedure. Any one of a number of things may go wrong and, when they do, nurses must

---

[17] During a strike among nurses in Quebec in October 1975, hospitals reported that patients were unable to undergo dialysis because the physician could not run the machines as competently as the nurses. C.B.C. television news, October 20, 1975.

respond quickly. As a result, competent nurses must be very well trained both in the operation, and occasionally even in the repairing, of kidney machines.

But nurses also feel some responsibility for the psycho-social management of dialysis patients. Their sense of responsibility is heightened by the fact that these patients must become very self-disciplined if they are to respond favourably to the treatment, and also by the fact that the nurses get to know their patients very well. Patients are dialyzed two or three times a week - for approximately eight hours each session, so that nurses can't help but develop some sense of responsibility for their welfare.

The net result is that nurses are responsible for both instrumental and expressive care,[18] that is - the technology of dialysis, and the psycho-social management of chronically ill patients. Although nurses seldom specifically address themselves to the question of their role,[19] their discussions of the nursing care of renal patients indicate that they do have a sense of dual responsibility. (Brand and Komorita, 1966; Sorenson, 1966; MacDonald, 1967; and Nesbitt, 1967).

---

[18] Johnson and Martin distinguish between instrumental and expressive care by defining instrumental care as the procedures done for and to a patient, whereas expressive care refers to meeting his emotional needs. See M.M. Johnson and H.W. Martin, "A sociological analysis of the nurse role" in The American Journal of Nursing 58, (3); 373-377, 1968.

[19] In the course of this research nurses on the hospital dialysis unit were asked how they perceived their role. All indicated that they recognized this dual responsibility. Most placed greater emphasis on the expressive aspect. As they put it, their first aim was to "support" the patient. They were divided on the desirability of becoming technicians (an instrumental task). In general the nursing assistants were more enthusiastic about their role - probably because they were indistinguishable from registered nurses, whereas some registered nurses fel they had moved too far away from traditional nursing and they were not required to "do enough for" the patients.

Depending upon the organization of the unit they may expect varying degrees of assistance from technicians on the one hand, and social workers, psychologists, psychiatrists and clergy on the other. This further complicates matters since it can then become problematic to determine where to draw the lines. That is, in both instrumental and expressive spheres the nurse must decide what is appropriate for her to do - and when she should call for outside help. To a certain extent her decisions must be based on the availability and accessibility of the experts. But these are practical considerations and our concern here is with a more basic problem.

The instrumental-expressive conflict experienced by nurses in a dialysis unit represents in microcosm the current problems of the profession as a whole. Nursing is often considered a semi-profession according to sociological criteria such as those enunciated by Etzioni (1969). Its quest for professional status is hampered by the fact that it has little expertise which it can claim as its own. Today there is a great deal of talk about "the expanded role" which, if realized, can enhance professionalization. But which way should nursing go? If it expands in the direction of technical expertise it runs smack into territory already claimed by physicians and technicians. And if it goes the other direction it collides with experts in the field of human relationships. The most notable conflict in this latter sphere is with social work - which is another semi-profession with heady aspirations for full professional status.

With some justification nurses may feel that they are a jack of all trades and master of none. Their professional mobility is blocked in almost every direction. Nurses in areas like renal units probably ex-

perience this dilemma even more acutely than others in more traditional settings. In some units, such as the one under study, the problem is further complicated by the fact that both practical and registered nurses may be hired as renal nurses, and the distinction between the two may be very blurred.

The role of nurses in a renal unit is both complex and challenging. They are being pulled in two directions.[20] For this reason students of professionalization should find the renal unit an interesting arena. It would be an exaggeration to say that the fate of the profession will be decided here - but what transpires in renal units may accurately mirror what is happening to the profession in general.

More recent literature indicates that the technicians are also professionalizing. Unlike the nurses the technicians seem to have a pretty clear idea of what they want and are clamouring for professional certification and all the benefits that accrue from such a process. To realize this goal, technicians state that they should have a rounded education in everything pertaining to dialysis. They see their role as intertwining with the nurse's, with the division of labour being determined by the institution, but it should be noted that if their education gives them access to some of the nurse's expertise that they may press for a role which allows them to use this knowledge. Technicians argue that they need certification for legal reasons - that is to protect them in

---

[20] The Edmonton Unit attempted to resolve this by experimenting with a "nurse technician." One of the nursing assistants was being trained as a renal technician. There appeared to be no clear-cut plan as to how she would be used, and she herself was not clear as to what she wanted to do. Of the nurses interviewed six (3 R.N.'s and 3 R.N.A.'s) favored the idea of combining roles, and three (2 R.N.'s and 1 R.N.A.) were opposed.

case of an error - but they also concede that this would bring them greater prestige and higher pay.[21]

Another intriguing aspect of professionalization concerns the patients themselves. Chronic disease may generate "professional" patients, particularly if they acquire some medical expertise with regard to their illness. If they also have access to one another their professionalization may emerge from an organized base. Long term dialysis fulfills these criteria.

A patient on a dialysis program is a very special type of patient and some aspects of his patient-hood are worthy of note. Like the diabetic, the dialysis patient must adopt a disciplined life-style. Not only must the renal patient follow certain dietary limitations, but he must also restrict his fluid intake. A number of different drugs may be indicated in order to minimize both the effects of the disease, and the dialysis itself. Again, like the diabetic, the dialysis patient must be carefully monitored since the treatment is highly individualized. The dialysis process itself varies from one patient to another. Some patients require longer, and/or more frequent dialyzing. Whereas the diabetic usually monitors his disease by testing his urine, the renal patient is more often checked by a variety of blood tests.

Almost all dialysis patients become quite sophisticated in their knowledge about their disease. Most learn to monitor themselves by simply assessing their sense of well-being, or by evaluating the presence or absence of various symptoms. Many centres encourage this process as an attempt to maximize the patient's independence, self reliance and

---

[21] See: Technician certification, J. Ren. Tech. 2 (2); 10-32, 1973.

sense of worth. Not only do these benefit the individual patient, but collectively the costs of the program can be reduced if patients can assume some of the responsibility for their own care.

In a further attempt to assist dialysis patients in normalizing to a high degree, some centres offer limited care, or home dialysis programs. Both of these approaches, but most particularly the latter, emphasize independence and self-care. For obvious reasons, the patients selected for these programs are usually both intelligent and responsible. It is not surprising then that many of them become as knowledgeable, if not more knowledgeable, than many staff members about renal disease and dialysis. Indeed many believe that they are experts in their own particular illness, if not in the disease in general. As patients become more cognizant of the degree of individual variation, they can become more confident about challenging the physician's recommendations. Although such patients can obviously become nuisances, they can also be very helpful. The latter is particularly true in experimental situations where, as Fox (1959) explains, patients can become partners in research.

For the most part, the staff who routinely care for dialysis patients are accustomed to dealing with knowledgeable patients. Problems are more apt to arise when renal patients are admitted to other areas of the hospital.[22] But even renal units can be expected to demonstrate some strain from this kind of patienthood.

---

[22] Many patients interviewed in this study complained that when they were admitted to areas other than the renal unit they were less likely to get direct answers to their questions, and their own opinions were not highly valued. One girl reported that the staff on a surgical unit ignored her request for a specific drug and she went into convulsions. Field Note, June 10, 1973.

Limits, for example, are a real problem. Just how much does the patient need to know in order to avoid complications and handle emergencies? At what point does the patient risk being overwhelmed by too much information - particularly about the hazards of treatment? When are the patient's interests best served by objective decisions which presumably the professional is better equipped to make? Individually, well-informed patients can be irritating; collectively they may be even more threatening. There is always the possibility that patients may organize if they feel that the staff are pursuing their own professional interests rather than those of the patients.

Renal patients are organizing. One such group in the United States drew up the Patient's Bill of Rights which specifies, among other things, that the patient has the right to complete access to information, choice of treatment and physician, competent professional care - including psychiatric, psychological and social services, as well as the right to refuse treatment.[23]

The patients at the unit under study had also formed a Kidney Patient's Association. A hospital administrator told the researcher that the association was making some unreasonable demands but he did not specify what these were. The staff on the unit seemed to regard the association as primarily a social club: the patients appeared to view it as primarily an opportunity for comradery and self-help.[24] Although the association did not at that time appear to be a lobbying force, that possibility always exists when people with similar problems organize.

---

[23] See: A patient's bill of rights. J. Ren. Tech. 3 (4); 53, 1974.

[24] Self-help groups of this type are discussed by Farquharson. See: A.H. Farquharson. Peers as helpers: personal changes in members of self-help groups. Unpublished doctoral thesis, University of Toronto, 1975.

Hints of the professionalizing patient could be discerned at the time of the study. One of the consequences of such a movement could have been predicted at that time but has only recently become evident. The trend to nurture more independent and knowledgeable renal patients led to a delegation of the doctor's responsibilities to subordinate personnel and patients. This had the effect of downgrading the importance of the physician within the renal unit. To a certain extent this backfired in that the American government then set very rigid controls on the amount of doctor-time it was willing to fund for dialysis patients. Renal physicians responded, in part, by forming a Renal Physicians Association which among other things asserts that:

> ...the interim guidelines by the federal government has resulted in a paralysis of payments to the providers of dialysis and transplant services. This has led to a corresponding hardship for patients. ...the Renal Physicians Association agrees that physicians attending patients should be directly reimbursed on a fee for service basis ... with quality of care and cost containment the responsibility of local peer review.[25]

In other words, renal physicians have responded to the professionalization of subordinate staff and patients by forming an organized specialty group within medicine - thus underscoring the professional status already achieved by medicine in general.

To date there has been little sociological analysis of these professional strivings. Such an analysis would be fruitful in its own right but it would also have implications for the questions posed in this particular project. If renal units are hot beds of professionalizing activities, this may well have a bearing on the development of patient

---

[25] For a more complete discussion of the Renal Physicians Association see: Renal physicians association, in J. Ren. Tech. 3 (2): 45, 1974.

careers. To a very large extent staff set the climate of renal units and in so doing contribute to the development of expectations for patient careers. If there is consensus about goals and timetable norms these may be determined, in part, by the staff. If patients themselves professionalize they may, in the future, have a stronger voice in determining the constraints upon their own behaviour - and that of staff as well.

C. The Psychosocial Aspects of Renal Disease

When we assess what is currently known about a patient's response to renal disease we are tempted to conclude that either there is a unimodel response to diseased kidneys - or that everyone is so unique that it is impossible to say much that is analytically useful. The truth is probably somewhere in between. Still, it is incredibly difficult to assess a response which is compounded by physiological, psychological, and social factors.

The importance of physiological factors is pointed out by Schreiner (1959) who explains that renal insufficiency produces chemical states which lead to personality changes. These changes may persist even after treatment, particularly dialysis, is instituted because dialysis only approximates normal kidney function. Generally speaking, psychological assessments of renal patients do not distinguish between the effects of disease, treatment or prognosis. Instead they speak in very general terms about the patient's fears surrounding changed body image, sexuality, and death - and about the use of defense mechanisms, such as denial, to contain these fears (Wright et al, 1966; Sand, 1965; Kemph, 1966; Crammond, 1966; and Kaplan-Denour, 1968).

The behaviour of renal patients could also be attributable to a

psychological response to diseased kidneys. Or there may be a specific response to treatment. Perhaps dialysis patients are responding to being dependent upon a machine, and transplant patients to being host to someone else's organs.

Presumably the psychological response to transplantation may vary depending upon whether the donor was a cadaver or a living relative. With the exception of Crammond's (1967) work few comparative studies have been done. If there is an identifiable psychological response to transplantation are cardiac and renal patients alike or different? To date this question has not been answered.[26]

Although further study in the psychological perspective may be useful, there is reason to suspect that a number of social or situational factors may also colour the patient's response. Some of the literature does refer to some such factors. For example, Shea (1965) and Abram (1968) concede that the experimental overtones in the treatment situation may potentiate psychiatric problems. Schreiner (1965) suggests that the screening process may have the same effect - especially if the patients conclude that their continued acceptance in a treatment program is conditional upon "psychological fitness.".

A number of authors refer to the practical and psychological problems facing the families. The practical problems are often economic since renal patients (particularly those on dialysis) may find it difficult to hold a steady job, and the treatment (again, particularly di-

---

[26] In a recent work Fox and Swazey touch on both cardiac and renal transplants. They suggest that the psychology of the gift has ramifications to both situations. See R. Fox and J. Swazey: The Courage to Fail, (Chicago, Illinois: the University of Chicago Press, 1974).

alysis) is expensive. In addition, the patient must be carefully managed in that his diet must be modified and his fluids restricted. The threat of death adds to the family's problems which are often categorized as "stress" (Wright et al., 1966; Cummings, 1970; and Cain, 1973).

Stress itself provides an additional perspective for viewing renal failure. For renal failure is, as Fox (1970) so cogently explains, shrouded in uncertainty. Uncertainty, she says, results from either limitations in the realm of medical knowledge, or the practitioner's incomplete mastery of available knowledge. Although individual practitioners treating chronic renal disease may have to deal with the second type of uncertainty, the first type - that of uncertain technology - is common to all. These "specialists in the problem of uncertainty" must daily balance the conflicting demands of research and patient care.[27]

Uncertainty is an intriguing human dilemma which has been noted as an important characteristic of other illness situations. Fox (1959), Davis (1963) and Roth (1963) all found that people tend to structure uncertainty in some way in order to make it more bearable. A common response used by patients is to compare themselves to others in similar circumstances and then to set up landmarks by which they can gauge their progress. Often their reference is someone who is worse off so that their situation, by comparison, looks more hopeful.

This structuring process may be regarded as a defence mechanism for coping with stress. Uncertainty undoubtedly generates a great deal of stress. Indeed as our conceptualization of stress becomes clearer it is increasingly evident that stress results, not from problems per se,

---

[27] The dilemmas created by providing treatment in a research setting are documented in an earlier work by Fox. Renee C. Fox, Experiment Perilous (Glencoe, Illinois, The Free Press, 1959).

but from the perceived discrepancy between the confronting problem, and the resources available to resolve it. In other words, a problem is a challenge as long as we are confident of our ability to master it. Stress arises when, for whatever reason, mastery is in doubt.[28] Uncertain situations, by their very nature, mean that a number of outcomes are possible, and the person is not sure which he should prepare to face. Equally important is the fact that he does not know how long the uncertainty will persist. These kinds of situations in which uncertainty is inherent, and indeed may even be institutionalized, must therefore be viewed as stressful to most participants.

Renal failure is certainly a stress situation. Stress results not only from the unknown outcome, but also from the course of the disease. Like other chronic illnesses such as cancer, renal failure may be characterized by slow decline. But renal failure carries the additional threat of sudden and unexpected complications which may be quickly fatal. In addition, each treatment method carries its own kind of stress. Transplantation is a life and death gamble on a cure. Dialysis imposes a more wearing chronic stress because it disrupts many aspects of the patient's normal life. To the extent that a patient chooses his own treatment situation he may be expressing his choice of stress situations.

Renal failure has some unique features which may generate very particular problems. These unique situations occur when the patient is dialyzed at home - or when a family member is the donor for a transplant. When research such as that done by Shambaugh (1969) has focused on situ-

---

[28] This view of stress is developed from the model presented by Scott and Howard. See: Robert Scott and Alan Howard, "Models of stress" in Social Stress. Edited by S. Levine and Norman Scotch. (Chicago: Aldine Publishing Company, 1970) 259-278.

ations of this type, it generally looked at the effect of the illness upon another crucial family member - such as the spouse or treatment partner. Usually the reaction of this person is described in psychiatric terms - such as the use of denial and displacement as defense mechanisms. Bailey et al, (1972) are able to break away from this mold of feelings and defense mechanisms to describe four types of response patterns for patients and their partners in home dialysis.

But there has been little study of the family as a unit. Kaplan et al, (1973) studied childhood leukemia and concluded that we should view the patients as a member of a family unit and that we should look at familial response to stress. As they state:

> It is important to emphasize family as well as individual reactions in coping with stress since the family has a unique responsibility for mediating the reactions of its members. When individuals belong to families they do not resolve their own problems of stress independently, nor are they immune to the effects of stress that may be concentrated in another member of the family. Vincent states that the family is uniquely organized to carry out its stress-mediating responsibilities and is in a strategic position to do so. No other social institution had demonstrated a comparable capacity for mediation that affects as many people in the community. (p. 60).

There is already strong sociological evidence such as in Durkheim's (1951) treatise on suicide, that the individual who is well integrated into a social unit is much more adaptable under stressful situations.[29] More recently other sociologists such as Parsons (Jaco, 1972) have pointed out the vulnerability of the nuclear family once illness strikes. This research, and the author's current study of leukemic children, in-

---

[29] The most striking example of suicide among the patients on the unit under study involved a young man on hospital dialysis who began to deteriorate when his wife left him. He neglected his dialysis routine, failed to show up for runs, and was eventually found dead at home. Field Notes, May 27, 1973.

dicates that the family, particularly the extended family, is of great import. Indeed, it would appear that rural patients frequently have an advantage over urban ones in that for rural patients the entire community frequently responds as if it were family.

In addition to mediating stress the family unit may be important in other ways as well. This study, for example, indicated that career decisions can be influenced by the family situation. Often an early decision to transplant seemed to occur when many members of the family came forward to offer a kidney. Some patients who were attracted to home dialysis dismissed it as an alternative because they either did not have a family member to serve as a partner - or because they thought it was too much of a burden to impose on one person. Conversely, some patients who were weak in their knowledge of the kidney machine were able to go on a home program because they had a partner who was mechanically inclined.

While on the one hand the family may protect, insulate or support the patient, it is also possible that illness affects the family. The family may, as some families in this study did, move in order to be closer to the hospital. The illness routine may alter the household routine. The roles which various family members played may change. Individual family members may react adversely to the stress, or the family unit may weaken and family breakdown may result.[30]

---

[30] This theme of psychological problems in other family members, and in break-down of the family unit, is common in the literature dealing with terminally ill children. Often it is poorly substantiated. One of the better works is provided by Hamovitch. See: M.B. Hamovitch, The Parent and the Fatally Ill Child, (Los Angeles: Delmar Publishing Co., 1964).

In short, a myriad of biological, psychological, and social variables compound the patient's response to renal failure, dialysis and transplantation. Much work remains to be done if we are to outline the interplay between these somewhat diverse variables. In particular the influence of the family in determining the patient's response, and the effect of the illness upon individual family members, and the family unit as a whole, has been very much ignored. Certainly it would appear that consideration of these factors is a more promising avenue toward the understanding of renal patients than that offered by an individualistic, psychological approach.

D. Dialysis and Transplantation as Sick Roles

Since the literature on renal failure offered limited insight as to how we may develop a sociological perspective on patient response to treatment programs we should determine if work done in other areas can be of value. The sick role may provide a useful conceptualization. In order to appreciate this perspective, some historical information on the development of the sociological construct of the sick role is necessary.

Although Parsons is usually credited with pioneering the concept of the sick role, that credit really belongs to Sigerist (Roemer, 1960). Briefly, Sigerist stated that following the influence of Christianity the sick came to occupy a privileged position which accorded them the right to be exempted from work, and to be cared for by others. These rights however, were, conditional upon the patient's sincere effort to recover.

Parsons (1951) cast illness in a more sociological light by pointing out that it is more than a natural phenomena - it is a role. It is, says Parsons, a motivated state sought by people in order to abdicate

their normal responsibilities. Since this kind of behaviour is clearly dysfunctional to society as a whole, Parsons saw the sick role as deviant. He added, however, that it was only deviant until it was legitimated by a physician. This legitimation, in turn, was conditional upon the patient's acceptance of his obligation to co-operate in his recovery. In short, Parsons conceptualized illness as a social role with institutionalized expectations and corresponding sentiments and sanctions.

A great deal of sociological research on the sick role has since demonstrated that Parsons' view was too simplistic. There is, in fact, a great deal of variation in behaviour associated with illness. For example, if two people experience the same symptoms one may seek medical help and the other may not. Sociologists have determined that this kind of variation may be attributable to culture (Saunders, 1954; and Paul, 1955), class (Hollingshead and Redlich, 1958; Koos, 1967), ethnicity and social organization (Suchman, 1965) and a variety of other variables. Twaddle (1969) suggested that pre-illness factors might be important. Among the subjects he studied, those actively engaged in jobs or hobbies seemed reluctant to acquiesce to symptoms. He also found that the inactive subjects tended to view themselves as sick, while the active ones did not. However, since the subjects were elderly it is difficult to determine if failing health leads to diminished activity - or whether inactivity increases one's propensity to give in to illness.

There is now general agreement that Parsons' described only one sick role - that of acute illness where symptoms are acute, painful and disabling (Goldstein and Dommermuth, 1961; Gordon, 1966; Twaddle, 1969). Variables such as age, sex, and socio-economic status have little effect on behaviour in these circumstances. Parsons' description may even hold

cross-culturally although the helper may not always be a physician.

Most of the variation noted by sociologists seems to be associated with chronic illness, and much of the difficulty in interpreting these findings seem to arise because social scientists have not clearly distinguished between acute and chronic illness roles. This may be why Gordon (1966) says that, in the final analysis, sick roles are very individualistic, and Litman (1969) talks about the importance of self-concept. Both Mechanic (1966) and Blackwell (1967) add that we need to come to grips with social psychological variables. What we need, it seems, is to develop a conceptualization of chronic illness roles which can account for the variation which has been noted.

Safilios-Rothschild (1970) drew upon a synthesis of previous work done on the sick role and postulated two responses to chronic illness which she calls acceptance and rejection of the sick role. Those who accept the sick role acquiesce to their illness or disability and enjoy the secondary gains, such as sympathy and attention, which accompany their new status. Those who reject the sick role eschew illness or disability, and the status associated with it, and attempt to normalize to a high degree.

She believes each response is determined by the interplay of psychological and social variables. These can be best understood by examining self-image, which according to Safilios-Rothschild, has both psychological and social components. The core features of our psychological sense of identity are bound up in care or key roles. For example, a woman whose psychological sense of identity revolves around her beautiful face may play the role of femme fatale in much of her social intercourse, or a man who particularly prizes his athletic prowess may play the role of

a jock. Illness or disability which threatens or shatters these key characteristics is particularly difficult to accept since the individual must restructure both his self-image and key roles. This is why, says Safilios-Rothschild, the loss of an arm may mean different things to different people. A loss of this kind may be disastrous to a labourer, but little more than a nuisance to a teacher.

In other words, whether one accepts or rejects the sick role depends upon both pre-illness characteristics, and the nature of the illness. This is a valuable insight since both responses have implications to recovery and rehabilitation. For, as she points out, those who accept the sick role are resistant to rehabilitation. On the other hand, those who reject the sick role co-operate very well with rehabilitation techniques but are disappointed if they can't be as normal as they once were.

This typology could be of real value in understanding the behaviour of patients with renal failure. The researcher noted, for example, that some patients seemed to display the behaviour associated with each role.[31] Despite their contrasting responses both were star patients who, by the force of their colourful personalities, were able to win the respect and admiration of patients and staff alike. In varying degrees the other patients tried to emulate both responses. To a certain extent these two responses appeared to be associated with treatment modalities. The role associated with acceptance appeared to be more common among patients on

---

31 Fox had made a similar observation in research on patients in an experimental treatment unit. Although she did not conceptualize these differences according to the sick role typology, she presented two case histories of patients who had made quite different responses to their illness. One accepted his disability with surprising equanimity; the other always strove to lead a normal life. Each in his own way, was a star patient. Other patients recognized both patterns and debated which was best. See: R. Fox, Experiment Perilous, (Glencoe, Illinois, The Free Press, 1959).

hospital dialysis, while rejection appeared to be more characteristic of patients on home dialysis or transplant programs.

Where renal patients are concerned, the question is whether the type of response is determined by pre-illness factors, or by the type of treatment program - or both? There are two reasons why this question is difficult to answer. The first is that the Safilios-Rothschild typology is not yet operational. Too little is known, for example, of what is meant by such concepts as "sense of identity?" The second lies with her emphasis on the nature of the illness. Which characteristics of the illness are important? This study of renal patients suggests that it is not the nature of illness, per se, which is important, but rather the nature of the treatment programs.

To use diabetes as an example, the important feature of diabetes may lie, not in the psychological response to a dysfunctioning pancreas gland, but rather in the response to the daily treatment routine - urine testing, injections, restricted diet and regular exercise. This view seems to be in accord with Goffman's (1963) work which states that the important features of disability are its visibility, and the extent to which it intrudes upon the patient's relationships with others.

If renal patients are divided, by choice (theirs or the staff's) into each treatment program, then we might be able to answer these questions by simply comparing patients in each treatment modality. Since the literature suggests, however, that such is not the case, then we need to acquire a great deal more understanding of renal patients before we can test the predictability of the sick role typology. The career framework is one way of acquiring this kind of data base.

E. Dialysis And Transplantation As Patient Careers

Julius Roth (1963) describes the experiences of T.B. patients according to a career framework. He defines career as follows:

> When many people in an interacting group go through the same series or stages of events in a given direction or on the way to a definite and recognizable end point or series of goals, we speak of this as a "career timetable", and of the consensus of expectations about when events should occur as "timetable norms" (p. 115).

The career goals of patients are obviously different from those of occupational groups. In a very broad sense all patients, including those with tuberculosis and renal failure, share the same goal, that of recovery. Recovery, of course, is a more realistic goal for T.B. patients than it is for those with renal failure. Survival is the more immediate goal of most patients and it may be that renal patients don't think beyond that.

Both tubercular and renal patients must contend with a degree of uncertainty. For the former, however, uncertainty is largely over timing. In fact Roth states that T.B. patients view their treatment program as "putting in their time" and in this respect they are similar to prisoners. For renal patients, however, the uncertainty pertains to outcome. This may mark the difference between purely chronic illness and those which are, to varying degrees, fatal. Some phases of renal failure, however, may approximate the sense of "doing time" which characterizes T.B. treatment. For example, those patients who are on hospital dialysis but awaiting home dialysis or transplantation may view their current treatment as "marking time".

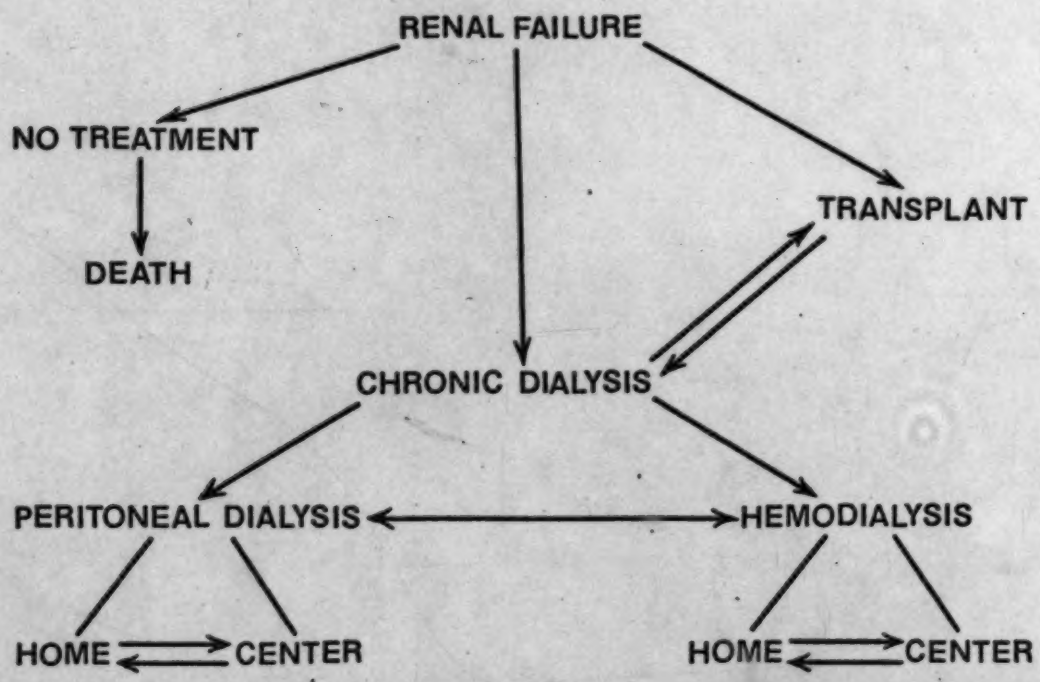
Roth stated that T.B. patients structure their uncertainty by developing time-table norms based on what is average or normal. Both

Roth and Davis (1963) noted, however, that when a patient seems to be exceeding the normal expectations that he, and his family, may then select another patient - who is doing worse - as a reference point. Studies of dying patients have also drawn attention to this tendency to compare oneself to someone who is worse off (Glaser and Strauss, 1968).

For the most part, medical norms dictate the tubercular patient's career. That is, it is the physician who determines how the patient will move through the career stages. By the use of various manipulative techniques T.B. patients can persuade the doctors to modify the time-table norms somewhat - but the patient's influence on the norms is limited. Furthermore, the doctors' decisions are usually based on medical grounds - x-rays, sputum tests, etc. Theoretically at least, the renal patient has greater latitude for personal choice. Where more than one type of treatment is offered he should be able to decide whether he is going to be treated by long-term dialysis (either hospital or home based) or transplantation. Medical considerations should dictate the choice only when there appears to be no other alternative. But do they?

Tubercular patients, as Roth outlines, don't always follow a straight line career course. For example, after several months of drug therapy a patient may be told that surgery is recommended. Or he may be shunted back and forth in a way that is out of keeping with the usual time-table expectations. According to Lowenthal et al (1973) however, these exigencies are even more characteristic of renal patients. He states that renal patients follow circular trajectories, and he illustrates this as follows:

Figure 1. Trajectories of Renal Patients



(p. 35)

As Lowenthal's diagram indicates, renal patients may be bounced in and out of hospital for any number of complications but, more importantly, their career routes may change. Transplanted patients return to dialysis when transplants fail - and some repeat the process two and three times. Hospital dialysis patients may enter a home care program. Some remain there indefinitely, others "graduate" to transplantation, and some are "demoted" to hospital-based dialysis again. In many respects, once a renal patient opts for treatment he is on a treatment treadmill and, unless he is unusually fortunate, he finds himself on a trajectory going around and around. Unfortunately, Lowenthal et al did not support their observations with data so it is not yet possible to ascertain how many renal patients may have this kind of experience.

Glaser and Strauss (1968) suggested that the trajectories of dying patients offer one avenue through which terminality can be further explored. The career perspective seems to be a more focused way of examining trajectories. The crux of whether or not renal patients meet the criteria, as posited by Roth, depends upon the extent to which they constitute "an interacting group". Patients who are on hospital based dialysis, or those who belong to a patient's association, certainly have the opportunity to interact and thus reach a consensus about norms and goals.

Using Roth's framework as a guide this study proposed to describe the careers of renal patients with a view to answering the following questions:

1) What are the career routes of renal patient - do they as Lowenthal et al (1973) suggest, shift from dialysis to transplantation and back again?
2) Do renal patients follow a particular career pattern progressing step by step through the same stages - or do they follow individualized routes? Are there distinct differences between those in each treatment category?
3) Who decides, and how are the decisions made, when the patient moves from one phase to another?
4) To what extent does the patient influence decision-making and is his choice determined by group consensus or individual criteria?
5) To what extent does the patient's illness career become the focal point of his life?

F. Summary

In summary, with the exception of the research on the moral implications of dialysis and transplantation, most of the studies on renal failure have focused on the psychological perspective and have not differentiated between the effects of the diagnosis, treatment, and prognosis. Much of this work has dealt with defense mechanisms and again this fails to touch on what is unique to renal failure. The few works which grasp some of the unique features of renal failure seldom deal with the significance of treatment programs. This project focuses on treatment modalities as the most significant feature of renal failure, and does so by viewing them as careers. One of the crucial questions within this perspective is the degree to which there is a consensus among patients as to goals and timetable norms.

Chapter III

THE STUDY: DESIGN AND DATA COLLECTION

As was earlier indicated, this study took place at a time when the staff of the dialysis unit were unsure about treatment goals. Should they emphasize dialysis or transplantation? And if dialysis, which type? Should they establish a limited care centre? And if they continued to offer a choice how should patients be selected for each program? These questions seemed to lead the staff, and most particularly the chief renal physician, to welcome the researcher as someone who might be able to shed some light on this dilemma.

The researcher was introduced to staff and patients alike as a social scientist who was interested in learning something about kidney disease. Although they must have had a few uncomfortable pangs at first, these were quickly dispelled as the staff grew accustomed to the researcher in their midst. Patients too, were probably a little dubious but they were already quite used to being medical curiosities. They had recently been approached by a nutritionist whose research required them to drink what they described as an unpalatable liquid. By comparison this research seemed innocuous and talking was welcomed as a way to pass the time.

The initial period was devoted to participant observation. For four weeks the researcher observed staff and patients in the area roughly known as the renal unit. The renal unit, as such, did not exist. But there was a network of areas throughout the hospital which served renal patients. These included the hospital dialysis centre, known as MP-5, - where the researcher spent the bulk of her time; the home dialy-

sis training centre, the out-patient department, and a medical ward where many renal patients were admitted for diagnosis or when complications arose.

Renal patients also went to other areas of the hospital - the operating and recovery rooms, intensive care, and the isolation area. But visits here were transitory and there were many times when no renal patients were included in the population there. Because time was short the researcher restricted herself to areas more commonly utilized by patients with renal failure.

Most renal patients were admitted to 43 (the medical ward) for diagnosis and stabilization of their disease. When their disease progressed to renal failure most were admitted, on an out-patient basis, to MP-5 for hemodialysis. After a period of time three distinct careers emerged - some patients remained indefinitely on hospital dialysis, some underwent training for home dialysis, and some received a kidney transplant. The reasons why patients chose, or were selected for the various routes were not clear and will be the focus of this report. Observations also confirmed Lowenthal's (1973) paradigm which indicated that patients sometimes select one course and then were rerouted on another. A systematic attempt would be made to find out how frequently this happened.

The first four weeks of the study was designed to be exploratory. Participant observation[32] was selected as the method of data collect-

---

[32] As Babchuk points out his method of data collection should more correctly be called "participant as observer". See: Nicholas Babchuk, The role of the researcher as participant observer and participant as observer in the field instruction. Human Organization (Fall 1962), 225-228.

ion for this phase. The purpose of this phase was to determine the feasibility of pursuing the career perspective and to gather data which could be used to describe:

(1) the setting of the hospital-based aspects of the patient careers.

(2) the interaction between patients, staff, and staff and patients with particular emphasis on the presence or absence of group consensus with respect to goals and timetable norms.

During this phase the researcher spent time in almost all areas frequented by renal patients - most particularly the hospital dialysis centre, the home training unit, the out-patient department and the medical ward commonly used by renal patients. The bulk of this time was spent in the dialysis centre and observations spanned all three shifts and included weekends. In addition, the researcher attended nursing reports (at the changeover of shifts), staff conferences, meetings, and consultations between physicians, patients and their families.

Three patient samples were selected for formal interviews. These samples included 10 of the 22 patients on hospital dialysis, 5 of the 10 patients on home dialysis, and 8 of the 18 transplant patients. Subjects in the hospital dialysis sample were selected by draw. One was rejected because of mental retardation. Subjects from both the home dialysis and transplant groups were randomly selected from those who were attending clinics on days when the researcher was available to conduct interviews. All patients consented to be interviewed and the interviews were conducted individually, sometimes in an office, and other times at the patient's bedside. The length of the interviews varied from 30 to 60 minutes with the average time being about 40 min-

utes.

The same interview schedule was administered to all patients. (See Appendix I for a copy of all interview schedules). In addition to the usual sociological information about age, sex, marital status, religion, religiosity, education and occupation, patients were also asked a number of open-ended questions pertinent to their patient careers such as:

(1) How long had they known that they had renal disease and how did they find out?

(2) What time interval elapsed between when they found out that they had renal disease and their first treatment for renal failure?

(3) What can they recall about their early treatment (dialysis) experiences?

(4) How long have they been undergoing treatment and what types of treatment have they experienced?

(5) Which type of treatment do they prefer, and why?

An attempt was also made to determine to what degree the illness career had impinged upon the patient's "normal"life. For example, patients were also asked if they had changed their occupation, moved closer to the hospital, joined the Kidney Patients' Association, and whether or not they considered themselves to be sick.

Formal interviews were also conducted with a sample of the nursing staff on the dialysis unit. The selection was random to the extent that nurses on duty were approached on days randomly selected for interviews - and all consented. Five of the nine registered nurses (R.N.'s) and four of the eight registered nurse's assistants (R.N.A.'s) were ap-

proached and consented to be interviewed. These interviews were conducted individually in a small office and each lasted approximately 30 minutes. Basic sociological information such as age, sex, marital status was requested. In addition, the nurses were asked to outline their nursing education and experience (See Appendix II). The remaining questions were designed to elicit data in two areas:

(1) the role of the nurse on the dialysis unit - how this compares to other units and which they prefer?

(2) the nurses' views on renal careers - the goals they would encourage patients to pursue and the type of treatment they would prefer for themselves?

Only two questions were formally put to the physicians. There were two reasons why more extensive formal interviews were not conducted. The first is that doctors are not captive in the same sense that patients and nurses are - thus formal interviews are more difficult to schedule; and the second reason was that the researcher was able to obtain a great deal of information from them during the observation phase. Unfortunately most of the observational data centered around two of the four physicians but these were the two most heavily involved in patient care (See Appendix III). The two questions put to all physicians were:

(1) What type of treatment would they recommend for patients?

(2) What would they choose for themselves?

The observational data were analyzed in such a way as to:

(1) describe the hospital setting.

(2) describe the interaction between patients, staff, and staff and patients with particular emphasis on interaction pertinent

to goals and timetable norms.

(3) augment interview data on patient careers particularly that on goals and timetable norms.

The analysis of data from patients examines what is common to all renal patients, the ways in which they differ - and the extent to which this difference is associated with the treatment situation. The analysis examines factors which lead to patient choice of career route and some of the possible consequences of choice.

Interview data from the nursing staff briefly examines their perception of the role of the nurse on a dialysis unit and how they compare this to nursing in other areas. The focus of the analysis of the data from this group, however, is on their treatment preferences. Comparisons are made between the R.N.'s and the R.N.A.'s and the responses of nurses as a group are compared to those made by patients and physicians.

Findings based on this data are presented in the following chapter.

Chapter IV

THE FINDINGS

A. Introduction

The patients in this unit came from throughout the province[33] - but primarily from the central and northern area. Subsequent to the establishment of this centre another had been set up in Calgary and that one then drew patients from the southern part of the province. The boundary lines were somewhat arbitrary but generally speaking patients from south of Red Deer went to Calgary. These were the only treatment centres in the province - with the exception of another hospital in Edmonton which offered only peritoneal dialysis. That unit, however, accepted patients who were not good candidates for either hemodialysis or transplantation - and many of them were referrals from the study unit. Renal patients in Alberta had, then, very little choice as to where they received their treatment.

Regardless of where they lived most patients were referred to the renal physicians by a local physician or family doctor. However, two of the patients - both of whom lived in rural Alberta - took the initiative in coming to Edmonton to see "a specialist". Since referral is the first step into the renal unit, it is possible that some patients - particularly in rural areas - are denied access at this level. Once the referral is made almost all patients are accepted for treatment. Although screening is denied,[34] the renal physicians readily conceded that they did not

---

[33] Two of the patients had originally resided outside of the province but had moved to Alberta when renal failure seemed a possibility.

[34] Screening may exist in a more overt form in the Calgary unit. One patient in the study unit had applied for treatment in Calgary and been refused.

accept patients who were too young, too old, or in poor general health.

The acceptance criteria are guidelines only and are not rigidly enforced. Generally speaking those who were under twelve were considered too young - and those over sixty-five were too old.[35] To the best of the researcher's knowledge only two patients refused treatment. One of these was a teenage boy whose parents refused on his behalf,[36] and the other a rather elderly gentleman who observed dialysis in progress and decided that that wasn't for him.

Since the sample for this study was drawn from only one treatment centre, we cannot determine how representative it is of renal patients elsewhere. However, since each sub-sample was randomly selected, it should be representative of the treatment group from which it was drawn.

The mean age for patients in all three sub-samples was 32.6 years - and, regardless of treatment groups the mean age varied little. The range, however, showed greater variability from one treatment group to the next. The greatest range in age was found among those on hospital

---

35 The unit had once accepted a six-year old girl whose renal failure was due to a surgical mistake. According to the staff her condition was difficult to stabilize and she had many crises. The staff were almost relieved when her parents finally refused further treatment and the child was allowed to die.

At the other end of the scale was a seventy-five year old patient who was referred to the renal physicians for consultation. They decided that the man's age, and his poor general health, made him a poor candidate for either dialysis or transplantation and they recommended that treatment not be considered. Field Notes, May and June, 1973.

36 This boy was the son of a nursing supervisor who worked in the hospital. Apparently, her professional experience convinced her that dialysis and transplantation were not acceptable for her son. The nursing staff who reported this incident seemed to agree with her decision. Field Notes, May and June, 1973.

dialysis whose age ranged from twelve to sixty years. No patient on home dialysis was younger than twenty-one years nor older than forty-six years. The youngest transplant patient was twenty-three, and the oldest was forty-nine years of age.

In all there were fifteen males and eight females. The male-female distribution on patients on hospital dialysis was even - there were five males and five females in the sub-sample drawn from this group. Only one of the five patients in the sub-sample of patients on home dialysis was a female. There were eight males and two females in the sub-sample of transplanted patients.[37]

The socio-economic status of the patients seemed to vary widely. By occupation they were students, housewives, farmers, labourers, office workers and even professionals. Their educational backgrounds also varied. Three had a grade eight education or less, ten had gone beyond grade eight but had not graduated from high school, two were high school graduates, and eight had some education beyond high school - but of these only two were university graduates. We will now take a closer look at the process - that of kidney disease - which brings these people together.

B. The Onset of Renal Disease

Renal failure usually develops slowly over a number of years. Almost all the patients reported that as children they had had some kid-

---

37 The predominance of males among these patients probably reflects the incidence of renal failure since the Canadian Dialysis Register notes that the majority of patients are male. See: Canadian Dialysis Register: a report on patients on dialysis in 1973, published by the Health Division Statistics Canada.

ney problems (urinary infections etc.) but for most of the patients these seemed of little consequence. For five of the twenty-three patients, however, these symptoms may have been significant. Four came from families with a high incidence of renal problems and the fifth was of unusually short stature and had grown up knowing that "something was wrong".

The way in which patients learned that they had a kidney problem varied considerably. One patient lost one kidney as the result of an accident when he was twelve years of age, and the second following another accident five years later. Eight patients found out about their renal problems when they received medical care for another reason - two were recovering from accidents; four were undergoing routine medical examinations (for school entrance, pilot's license etc.); and two were pregnant. (Both of the women who were diagnosed during a pregnancy subsequently became pregnant again and the pregnancies were terminated. This procedure convinced them that their problems were becoming serious). In all, nine patients were asymptomatic at the time of the initial diagnosis. The remaining fourteen patients developed symptoms (such as fatigue, general malaise, weight gain, swollen ankles, blurred vision or bone problems) which took them to the doctor and thus lead to the diagnosis. Of course not all patients who develop a kidney problem will progress to renal failure, and therefore these patients did not necessarily anticipate failure.

C. From Diagnosis To Failure: The Waiting Period

The period of time between diagnosis and the onset of failure, and hence treatment, varied widely. Three patients were treated conserva-

tively for less than six months before undergoing dialysis, one waited almost a year, and ten waited from one to three years. A further nine were followed from three to ten years. (The median waiting period was one to three years but almost as many patients waited more than three years).

Waiting implies that the patients knew what was in store for them - that is that they were destined for dialysis or transplantation. Such was not necessarily the case. Here is how some patients described the onset of the disease and the waiting period:

(1) "My mother had died of kidney disease. I remembered it as a horrible illness and a horrible death. Ten years ago I got sick. For seven years I was on pills but I just got worse and worse. I didn't know anything about the machine - I just thought there was no hope for me. Finally I thought I would kill myself and then the doctors sent me here." (Female, age 48 years, hospital dialysis).

(2) "I seemed perfectly healthy until I was eighteen. I applied to go into nursing school and was rejected because I had a kidney problem. I was told that if I married I shouldn't have children but other than that it made little difference. Then six years later I suddenly went into failure and they flew me here." (Female, age 28, currently on home dialysis - with 2 previous transplants).

(3) "I had a few attacks of nephritis but I didn't think it was serious. For four or five years it was quiet and then I suddenly went into failure. I was flown here and put on dialysis." (Male, age 28, transplanted).

Generally speaking, patients who developed renal disease during the early days of treatment were likely to know that failure was possible, but not likely to know that treatment was available. Most patients initially learned about dialysis and transplantation from the renal physicians - and thus rural patients tended to learn later in the course of their disease than urban patients. On the other hand, as treatment be-

came a common part of public knowledge patients were less likely to believe that there was no hope if failure developed. Indications are that patients were not given any indications of the odds for survival - unless they asked - and few stated that they did so. When questions about prognosis were asked the physicians generally answered in couched terms which emphasized the positive factors such as, "Well, it is really difficult to say but some patients have lived a long time and we feel that the outlook is getting progressively better."

D. The Anticipatory Stage

Most patients were told something about dialysis before they encountered it, but the preparation they received varied widely. Here is how some patients described the anticipatory stage:

(1) "About a month before I went "on", I was told about the machine. I even visited the unit and met some of the patients. I was pretty well prepared - sort of ready to take whatever came." (Male, age 28, hospital dialysis)

(2) "I had had problems for about a year. Then the kidney machine was mentioned. "Oh no," I thought "not that." I was brought to the ward to see the machine but the patient using it had convulsions. That made me nervous. The doctor also told me about home dialysis but my wife can't stand the sight of blood and my son was too busy to be my partner." (Male, age 60, hospital dialysis).

(3) "I had had problems for about a year. About a month before I went on the machine I was brought to the unit. By this time I wasn't feeling so hot and the patients on the machines looked so well that I couldn't wait to try it." (Male, age 29, home dialysis).

(4) "I was aware of the machine long before I went on dialysis but I never saw one until I needed it." (male, age 46, home dialysis)

(5) "I was only sick for five weeks before my first dialysis so I didn't see the machine first. I was quite sick during my first run but I was still

anxious to learn about the machine." (Male, age 23, transplant).

(6) "I had been sick for six months and regulated by diet. Then I went on peritoneal dialysis. But I didn't respond. I was told about the machine then I was terrified. Then I met a boy who had tried it and he said it was great. That helped." (Female, age 46, transplant).

The data suggest that when failure developed according to schedule there was a deliberate attempt by the renal physicians to gradually introduce the prospect of dialysis and to arrange for the patient to see the machine about one month before he required it. The evidence also suggests that this introductory program was more common among recent patients. Unfortunately, however, as Glaser and Strauss (1965 and 1968) pointed out with dying patients, medical practitioners do not always have an infallible sense of timing. Just as patients may die sooner or later than is medically expected, a renal patient may also develop failure more or less quickly than was anticipated. Ten of the twenty-three patients described being rushed to the hospital, often by plane, when failure suddenly ensued.

E. The First Dialysis Experience

Ten patients spent a short period of time - usually a few days, on peritoneal dialysis before trying hemodialysis. For the most part these were the patients who suddenly went into failure and required dialysis very quickly. (Hemodialysis must be preceded by a relatively minor surgical procedure in which the cannula is inserted). None of the patients recalled peritoneal dialysis as a particularly dramatic experience but most reported that they were only slightly improved as

as a result. For almost all patients, however, running[38] on the machine was a major event in their illness careers. Here is how some described it:

(1) "My first run is hard to remember. I was pretty sick, vomiting and all that, but everyone was cheerful and that helped." (Male, age 28, hospital dialysis).

(2) "Rotten, rotten. I felt rotten. I had a headache and I was freezing. It hadn't bothered me to see other people's blood in the machine but it bothered me to see mine." (Female, age 12, hospital dialysis)

(3) "Well, for four hours I felt good. Then I blacked out. But the machine itself didn't bother me - I am a mechanic. And the sight of blood didn't bother me, either. My wife wasn't upset either. In fact, the staff thought she was a nurse." (Male, age 29, home dialysis).

(4) "I was extremely ill before I went on the machine - I was having convulsions. So I don't remember it too well. I remember being cold but I refused to complain. The machine itself didn't bother me - still doesn't." (Male, age 46, home dialysis).

(5) "I don't remember how I felt physically but I remember thinking that it needed to be done, and that I would get used to it. I think it helped that other patients had explained it all to me - and better than the doctor." (Male, age 26, transplant).

(6) "I was quite sick at the time but I was delighted to see the food. They gave me onion soup - I love it and hadn't been able to have it for a long time." (Male, age 23, transplant).

Almost all patients were quite ill when they were first using the kidney machine and most reported adverse reactions to dialysis - nausea,

---

[38] A session on the machine is referred to as a "run". Patients were on a regular dialysis schedule which usually called for three runs per week. The length of the run varied but was usually between 6 and 8 hours and most patients developed a standard running time.

vomiting, feeling cold, etc. This reaction was almost standard and this suggests that it is largely a physiological raction and is unrelated to psychological factors. On the other hand, patients seemed to distinguish between physiological and psychological reactions - and greater variability was evidenced in the latter area. Those who were comfortable about machines in general, or the kidney machine in particular, seemed less fearful. Response to the sight of blood - particularly one's own - also seemed important.

F. Adjusting to Dialysis

Almost all patients found that, with time, they became both physiologically and psychologically accustomed to dialysis and felt quite well. Some, however, found that they never did really adjust to it. The following represents the responses of seven of the eight transplant patients:

(1) "Physically and psychologically I just didn't adjust to the machine. I was depressed, irritable, and difficult to live with. From the very beginning I wanted a transplant." (Male, age 23).

(2) "I tried to take everything in my stride. But I didn't feel well on dialysis. I had no energy. I was depressed. I was down to 80 pounds. Now I have been reborn." (Female, age 46).

(3) "I was dragged out all the time and not able to work. That's not much of a life. Besides when I first got sick I met a patient who had a transplant. Right away I talked to the doctors. All the time I was on the machine I was just waiting." (Male, age 26).

(4) "It was awkward trying to plan my life around the machine. Now I lead a normal life - and going to the bathroom is such a thrill." (Female, age 37).

(5) "The machine was just a way to keep alive. I was on it eight months but from the beginning I wanted a transplant. It's like being re-born." (Male, age 48).

(6) "I like to think I was interested in a transplant all along. For over a year I just waited. I never considered home dialysis - I don't want the damn thing around." (Male, age 26).

(7) "I wouldn't have started if I had known how bad the machine was - it was terrible." (Male, age 49).

The eighth patient had been on dialysis for six years (approximately one year of it at home) and stated he reluctantly accepted a transplant because of bone disease. His seven cohorts, however, disliked dialysis. Three indicated that for physiological and or psychological reasons they did not respond well to dialysis as a therapy. Four objected primarily to the dialysis routine - to them being tied to a machine interfered with the rest of their lives.

None of the patients on dialysis reported the same distaste for the procedure. One of the patients on home dialysis did state that the hospital environment disturbed him. He put it this way:

> "I was going "owly" in the hospital. I found it (the hospital) depressing and asked to see a psychiatrist. He said it was a psychological reaction. The doctors suggested I go on a home program. I was glad - its good to get away from people with sick mentality." (Male, age 46).

In short, patients on home dialysis did not express distaste for dialysis, nor the dialysis routine, but three of the five patients in this group disliked undergoing dialysis in hospital because it brought them into contact with people who thought of themselves as sick, and interfered with their desire to be "normal". (The remaining two stated that they had no particular objections to hospital dialysis but they lived too far away from the hospital to make this a viable option).

G. Changing Courses

All patients spend a period of time on MP-5 on hospital dialysis. Theoretically, the decision to change courses could occur at any time. Of the thirteen patients in the samples who opted for either home dialysis or transplantation, none made the change until they had spent at least six months on hospital dialysis. Seven made the decision after less than four years on MP-5, and the remainder after more than four years on hospital dialysis. Those on home dialysis spent an average of two years on hospital dialysis. In this instance, however, the waiting period may not reflect the length of time required to make the decision - but rather is probably related to the availability of home dialysis.[39] Indications are that the waiting period is diminishing. Home dialysis is being offered to all new patients and if they express interest, plans are made to begin formal training almost immediately.[40]

Five of the eight transplant patients were transplanted after less than a year on hospital dialysis. The remaining three spent up to six years on MP-5. This finding suggests that early and late decisions to transplant may result from two very distinct decision-making processes and later these will be discussed in greater detail.

---

[39] Prior to 1973 only two patients had attempted home dialysis. One of these came from a rural area and the people in his community covered his expenses. The second was the gentleman, who happened to live in the city, who reported psychiatric problems related to hospital dialysis. When the provincial government agreed, in 1973, to fund home dialysis this centre began a formal training program.

[40] This is what happened with a newly diagnosed patient awaiting admission to the training programs. The nursing staff on MP-5 began her training and frequently praised her decision to dialyze at home. Every attempt was made to reinforce her decision and to treat her like a guest who wouldn't be on MP-5 for very long. Field Notes, May and June, 1973.

H. The Treatment Treadmill

How many of the patients in the sample had changed courses more than once? None of the ten patients on hospital dialysis had tried either home dialysis or transplantation. Two relatively new patients, with less than six months on dialysis, were awaiting a change - one to home dialysis, and one to a transplant. With two exceptions the patients on home dialysis appeared relatively stable. One of these two exceptions had been transplanted twice - and expected to be again. The other periodically reverted to hospital dialysis - several times - because he did not manage himself well at home. Of the eight transplanted patients one had attempted home dialysis. Another had reverted to hospital dialysis between his first and second transplant. And one of the patients in this group rejected his kidney before this research was concluded and consequently returned to hospital dialysis.

In sum, surprisingly few patients had opted for home dialysis or transplantation and then changed routes again. This is probably due in part to the fact that home dialysis was relatively new - and to the fact that many of the transplanted patients had died. Although there is less indication of the treatment treadmill effect than we might have expected, this does not necessarily mean that patients pursued the career of their choice.

I. Treatment Preferences

The researcher had expected that most patients pursued their treatment choice. This would seem to be substantiated by the fact that few had changed courses more than once. As Table I illustrates, such was not the case.

Table I - Treatment Preference* by Current Treatment Modality

Current Treatment Modality	Treatment Preference			
	Hospital Dialysis	Home Dialysis	Transplant-ation	TOTAL
Hospital Dialysis Patients	4	1	5	10
Home Dialysis Patients	-	1	4	5
Transplanted Patients	-	-	8	8
TOTAL	4	2	17	23

*Treatment Preference is the first choice of patients in each treatment group.

The patients in the hospital dialysis group demonstrated the greatest variability with respect to treatment choice. The four who selected hospital dialysis rejected home dialysis as impractical for them - or more correctly for their families. Three of these patients were siblings and they indicated that their mother would be constantly running the machine if they opted to dialyze at home. The fourth was a single male who did not reside with his parents. All four of these patients rejected transplantation as too risky. Some of their comments were:

> (1) "I've thought of a transplant but I don't want one. My friend Terry[41] had one and she died, and then there is Jimmy (the patient whose second transplant failed and who was mentally retarded as a result of post-operative complication). I've known a lot of (transplant) patients who died and so many (living) transplant patients are in hospital now. I'm also afraid of prednisone (a cortisone derivative given to transplant patients). It changes your looks and I don't want to change my face. And it changes your personality and makes you depressed." (Female, age 19 years).

---

[41] Names have been changed throughout to ensure the anonymity of all patients in the study.

(2) "The doctors have often suggested a transplant to me because of my bone disease. But I will stay where I am right now - its safer." (Male, age 23 years).

(3) "Right now I don't need a transplant so I'll wait until the chances are better." (Male, age 38 years).

The one patient who selected home dialysis was newly diagnosed and awaiting training for these procedures. Her reason for selecting home dialysis was that she lived too far to come to the hospital. She did indicate, however, that she had thought about a transplant but when a doctor explained the risks she rejected the idea.

Of the five patients in this group who said that transplantation was their choice, two had been diagnosed within the past six months. One of these was going to receive a kidney from a family member. The second, a sixty year old male, said that the doctor had told him it wasn't a good idea but hadn't explained why and he still wanted one. The remaining three were "old hands" and had been on dialysis for three to five and one-half years. Their comments were as follows:

(1) "When I first got sick I told the doctor that I wanted a transplant. I've met some patients who have had one and they are doing well. I'm just waiting..."(Male, age 28 years).

(2) "I used to be afraid of rejection but I'm less afraid now. The doctor says I have to wait at least another year." (Female, age 48 years).

(3) "It (a transplant) was suggested to me when I just got sick but I didn't want one. Transplants are risky - the patients have problems. Now you might say I'm itchy. Five years is a long time to be tied to a machine. I'm tired of dialysis. Now I am ready for a transplant." (Male, age 34 years).

For four of the five patients on home dialysis, dialysis at home was preferable to dialysis at the hospital but they still looked for-

ward to a transplant. Some of their responses were:

(1) "I prefer home to hospital (dialysis). But I want a transplant. I don't know if I am on the (waiting) list." (Male, age 23 years).

(2) "I've had two transplants - rejected both, but I am going to try again." (Female, age 28 years).

(3) "Right now things are going well so I'm not as eager as I was a couple of months ago but I would sure take one (a transplant) if it came up." (Male, age 29 years).

(4) "I used to be afraid of a transplant - I have a phobia about infection. But I've been on dialysis for five years now and so if a good match came along I'd take a transplant." (Male, age 46 years).

The one exception in this group said:

"All told I have been on dialysis for seven years and I never seriously thought about a transplant. Rejection is a major problem. Besides I've been in good health." (Male, 29 years).

All of the transplant patients cited a preference for transplantation. This preference held even though they had not necessarily wanted one when they first got sick - and despite the fact that three of them were not very well.

Looking at the total picture, roughly 50 percent of the patients were in the treatment modality of their choice. Of those who did not have their first choice, all were able to pursue their second choice.

The researcher had expected that the staff would all favour home dialysis. This assumption was based on the observation that they were always on the look-out for new candidates for home training, and also that they frequently discussed how well the graduates seemed to be.

When the physicians were asked which modality they preferred for patients they confirmed the researcher's expectations - with the one

advocating transplantation and the others supporting home dialysis. However, when they were asked what treatment they would choose for themselves all seemed surprised - as if they had never thought in terms of personal choice - and the three non-transplant advocates gave a very similar response:

> "Well, I wouldn't choose hospital dialysis - that's no life. I guess I would go on home dialysis. No, on second thought, I'd take my chances with a transplant."

The nurses' responses were a little more mixed. Again all thought that home dialysis was the treatment modality which should be pushed for patients, but for themselves, four of the five R.N.'s and one of the four R.N.A.'s would opt for a transplant. Like the doctors they said, "I guess I would try it and hope that it worked." The four exceptions all selected home dialysis.

Those members of the staff who said that they would likely chance transplantation for themselves seemed to be saying that while they thought home dialysis was the treatment of choice, it was a demanding program and they might gamble on a transplant. It is not likely that the patients knew, or even sensed, what the staff would pick for themselves. Most patients felt that staff favoured home dialysis - and it was in the milieu that their own treatment decisions were made. Later we will look at the process of decision-making or choice, but first let's examine some of the consequences of renal failure and the extent to which these might be affected by treatment modality. These will give us some understanding of the impact of renal disease, and the treatment programs. Some of these may be considerations which the patients weigh in determining their career choices.

J. Some consequences of Renal Disease and Treatment

If patients observe what happens to other patients and use these observations in making decisions about themselves, some of the factors they may consider are:

(i) The Decision to Marry

Eleven of the twenty-three patients were married. Some of these patients spoke of the importance of their spouse to their survival. One patient put it this way.

> "If it were not for my wife I just wouldn't have made it this far. You have to have something to live for." (Male, age 30, transplant)

Another, however, spoke of the strain that the illness, and the resulting financial problems, placed upon his marriage:

> "I've been sick for three years. In the past two years I've been unemployed for 18 months. We're always broke and it's a drag being around the house so much. You learn that you can see too much of a person. My wife would like to "get out from under it all" but with two small kids, a sick husband, and no money, she's stuck." (Male, age 26 years, transplant).

Two patients, both transplanted, were divorced or separated. In both instances the marriages had broken while the patients were on hospital dialysis and each attributed his marital problems to his illness.

With one exception, the single patients were on hospital dialysis or had been transplanted. This suggests, and the patients and staff agreed, that a spouse is almost a pre-requisite to home dialysis. But it also suggests that if a single patient is to endure dialysis he needs the support which the staff could provide in the hospital setting.

Both staff and patients seemed to view dialysis as more demanding than transplantation upon the marriage situation. Impending marital breakdown

seemed to be one of the social reasons which led the doctors to push for transplantation. Staff also tended to view home dialysis as beneficial to the family since the patient was highly normalized and could spend more time at home. None of the patients in this group challenged this assumption. But one patient in other programs did. As he said:

> "I've been watching these patients on home dialysis and you can't tell me that it isn't hard on their partners. It's an awful burden to place on anyone and that's why I wouldn't consider it." (Male, age 37 years, hospital dialysis).[42]

Although some of these patients married when they were clearly brewing renal problems, none had married after the onset of renal failure. Since many of them were young this might simply be a function of age. However, of the thirteen patients who were between twenty-one and forty years of age, seven were single. None of the patients stated that illness had any affect on a decision not to marry, but the fact that many of them were not married and gave no indication that they were considering marriage, suggests that it may.

(ii) Residence

Nine of the twenty-three patients reported that they had moved closer to the hospital after the onset of renal failure. Six of the ten patients on hospital dialysis had made such a move - and so had three of the eight transplant patients. But two of this latter group said that they had moved while they were on dialysis. None of the patients on home dialysis had

---

42 As home dialysis becomes more common the incidence of marital breakdown may confirm this patient's expectation. At the time of this study, however, there was a general reluctance on the part of both patients on home dialysis, and the staff, to concede that this modality might have adverse effects upon marriages. Both groups seemed constrained to prove that home dialysis was the treatment of choice and that it could live up to their expectations.

moved closer to the hospital - in fact one had moved from the city to a farm. Of those who moved three were housewives and four were dependents and, in all these instances, a move for the patients meant a move for the entire family and usually a new job for the breadwinner. Those patients who do not live close to the hospital and cannot, or will not, require their families to move find that this limits their treatment choice to either home dialysis or transplantation.

(iii) Occupational Choice

Few patients reported that their illness had in any way affected their choice of occupation. One stated that her problems with "frequency" had been one of her reasons for dropping out of high school.[43] Those who were still students felt that their illness had not affected their occupational goals - however, it appeared that they had in effect narrowed their range of choices to those which were likely to be compatible with either their disease or their illness routine. Four reported job changes subsequent to their illness - and in three instances this appeared to be a consequence of the disease. One of these three, for example, had been in business with his father. As his father grew older, and he became more incapacitated by his illness, it became obvious that the family business had to go and the patient sought another job. There were no reports of vocational rehabilitation following the onset of the failure.

(iv) Employment Status

Although employment seems straightforward, it can be difficult to define. For our purposes students were considered to be "employed" and

---

43 The twelve-year old girl in the hospital dialysis group was having a difficult time keeping up with the school work. The doctors suggested that she attend a special school for the physically handicapped but she found the idea unappealing. (Field Notes, June 3, 1973)

housewives were classified as "unemployed". This somewhat unorthodox definition was applied because our prime interest was in determining the effect that the illness had upon the patients' pre-illness work lives. For that reason students who managed to continue to go to school were considered to be "employed". Housewives were considered as unemployed because it was difficult to determine the extent to which the housewife continued to perform her duties as she had done prior to becoming ill. (Housewives were asked, however, if they had previously been gainfully employed). By these criteria fourteen patients were "employed" and nine were "unemployed". Just what this means becomes clearer if we also take a look at education.

Education was roughly categorized into five levels and patients were assigned to the level which included the last grade they have attended or the highest level they achieved. The five levels are:

1) Level I - those who reached grade eight or less
2) Level II - those who went beyond grade eight but did not graduate from high school
3) Level III - those who graduated from high school but had no further education or training
4) Level IV - those who had some education beyond high school but were not university graduates
5) Level V - those who had a university degree

Table II depicts the educational levels attained by the patients in the three treatment groups.

Table II - Educational Attainment by Treatment Modality

TREATMENT MODALITY	EDUCATIONAL LEVEL					
	I	II	III	IV	V	Totals
Hospital Dialysis Patients	2	3	-	3	2	10
Home Dialysis Patients	0	2	1	2	0	5
Tranplantation Patients	1	5	1	1	0	8
T O T A L S	3	10	2	6	2	23

The patients on hospital dialysis are distributed at both ends of the education scale. The five unemployed patients in this treatment group are all found in levels I and II. Four of these five people stated that their unemployment was a direct consequence of the illness. They had previously been employed in manual or factory jobs, and reported that their illness, or the dialysis routine, made it difficult for them to continue to work. One of these is now an unemployed housewife and she stated that her husband does most of the household chores. Three of the five "employed" patients at the other end of the scale are university students. They, like the two who were gainfully employed, found that their work could be structured around their dialysis routine. However, the students had to schedule classes around their runs and were not always able to take on a full class load. One of those on salary left the family business for a less demanding job.

Senior patients were quick to point out that newer techniques, which keep their hemoglobin at close to normal levels, make it easier to lead a normal work life. Before they struggled through with hemoglobins as low as 25% that of normal. In those days even minimal exertion required tremendous will power. Still, it was difficult to hold down a job while on hospital dialysis.

Not surprisingly, patients on home dialysis had reached at least level II. With one exception, all patients in this treatment group were employed. Those who were employed tended to be self-employed - either farmers or self-employed businessmen. The one unemployed patient was a housewife who had not been employed prior to her illness. She did, however, manage all of her household chores just as she had always done.

Most of the transplanted patients were in educational levels II, III, and IV. Only one had less than a grade eight education and none were university graduates. Health seemed more important than education for the employment prospects of the patients in this group. Of the three who were unemployed one was a housewife who had not worked previously, and the remaining two were disabled men. (One was crippled - the other blind and crippled). Both reported that they had been employed while they were on dialysis. Furthermore, two of those who were currently employed reported that they had been unable to work while they were on dialysis and were now able to do so.[44]

Obviously, of the three treatment modalities, hospital dialysis is most incompatible with work. Dialysis patients are not able to do heavy physical work. Furthermore, the dialysis routine cuts into work hours unless the patient runs at night. (And even when he does it usually means that he gets less sleep on those nights and is tired the next day). Skilled, professional or self-employed patients are best equipped to modify their work patterns and still remained employed.[45] Unskilled workers are at a distinct disadvantage and unless they are highly motivated to work they are likely to become unemployed.

Staff were unanimously agreed that patients should work. Employed patients who were on hospital dialysis got the preferred dialysis schedules

---

44 This does not mean that transplant patients who are well enough to work may not have difficulty getting a job. One of the patients, a divorced mother, asked the doctor what she should tell her perspective employer about her health and how she should explain her need to take one day off a month to go to clinic. Field Notes, May 28, 1973.

45 One patient on hospital dialysis reported that he was fortunate in that both he and his son worked for the same employer and that his son would "cover" for him when he was not well. Field Notes, May 25, 1973.

- which were nights with week-ends off. When the dialysis routine made it difficult for a patient to work, staff would urge him to consider home dialysis. When the disease itself made it difficult for the patient to work transplantation was often suggested.

Some patients agreed with the staff expectations regarding work. One of these, a university student who was crippled with bone disease said:

> "I am proud of what I have been able to accomplish. It has been hard but I never ask for favours. Few of my professors, and none of my classmates know exactly what is wrong with me. I don't tell them because I don't want to be treated differently. When I think of what I have been able to do in spite of it all I feel good." (Male, age 23, hospital dialysis).

Some patients, however, did not seem particularly keen about work. They did not put these views into words but their behaviour suggested that they disagreed with the work ethic. One of these, a young man who had been refused treatment by another unit, flitted from job to job and was frequently unemployed. Staff regarded him as a failure and sometimes discussed whether or not he was worthy of treatment. Another patient was not censured in the same way because, although he was on welfare and expressed no desire to work, he compensated for it by otherwise being a model patient. This particular patient actually seemed to enjoy his special patient status - and he was one of the few who could get away with it.

Whether or not the patients agreed with the expectation to work, all knew that it existed and that if they violated this expectation, either because it was simply too difficult or they really didn't care, they could expect to be censured in some way.

(v) Social Life

If it is difficult to work, what happens to other aspects of a patient's "normal" life such as social life? Let's look first at membership in the Kidney Patients' Association. The association was primarily a self-help group which promoted fellowship among patients and provided practical assistance. The assistance was usually in the form of comfort supplies (such as hot water bottles) for MP-5, though occasionally outings were planned - especially for patients on hospital dialysis. Since some patients expressed an interest in the association but said they rarely attended meetings, membership status was divided into three categories: (a) active member (usually attends meetings), (b) inactive member (rarely or never attends meetings but holds membership), and (c) non-member. Table III illustrates the relationship between membership status and treatment modality.

Table III - Status of Membership in the Kidney Patients' Association by Treatment Modality

TREATMENT MODALITY	MEMBERSHIP STATUS			
	Active Member	Inactive Member	Non-Member	TOTAL
Hospital Dialysis	0	6	4	10
Home Dialysis Patients	1	2	2	5
Transplant Patients	3	2	3	8
T O T A L	4	10	9	23

Patients on hospital dialysis generally expressed an interest in the Kidney Patients' Association but stated that they were not well enough to attend meetings - or that their dialysis routine left them with little free time. Those who were inactive members tended to be employed or else were students.

Generally speaking patients on home dialysis expressed little interest in the Kidney Patients' Association. Those who held memberships had obtained them while they were still on hospital dialysis. The one active member from this treatment group stated that he felt obligated to attend meetings because he was well and lived within the city.

The transplant patients, as a group, expressed the greatest support for the Kindey Patients' Association. Whereas the patients in the dialysis groups tended to state that the association was a good thing for those who needed it (and few of them saw themselves as needing it) the transplant patients saw the organization as one intended to help "those poor unfortunate people still on dialysis", and they felt some moral obligation to support it.

Perhaps membership and participation in the Kidney Patients' Association is, as the patients seemed to indicate, dependent upon how well they are, how much free time they have, and how close they live to the hospital. The high percentage of non-members, however, suggests another explanation.

It appears that most patients felt that the association existed to help patients on dialysis, and although most added that this was "a good thing" it is not at all certain that they really meant it. No patient on hospital dialysis conceded that he personally needed it, and most patients in this modality thought that the rigours of his treatment schedule should exclude him from active participation. Most patients on home dialysis seemed to believe that they were excluded from any obligation to support the organization. Indeed some gave the impression that the association was a part of an illness situation to which they no longer belonged. Transplanted patients, on the other hand, seemed to feel that unless they were

disabled they were morally obligated to help those less fortunate then they. True, the patients on home dialysis could feel the same way - and the difference may be that the patient on home dialysis has "earned" his own way out of the hospital - and the transplanted patient is indebted to someone else.

If few patients regularly attend the Kidney Patients' Association, what happens to pre-illness activities such as church attendance? The patients came from a variety of religious backgrounds - eighteen were Protestants, one was Roman Catholic, one Greek Orthodox, and three stated that they had no religion. Only three patients reported a change in church attendance following their illness. All of these patients were on hospital dialysis and all stated that they used to attend church more than once a week but that they were not able to attend as often because of their dialysis routine. A further five patients said that they attended church at least once a month and that no change had resulted because of their illness.

It is interesting to note that all of the patients on home dialysis said they rarely or never attended church.[46] It is also worthy of note that, irrespective of treatment modality, not one patient expressed an increase in religious fervour or church attendance following renal failure. If living with a life-threatening illness affected their philosophy of life this was not reflected in religious behaviour.

---

46 Rotter states that people vary according to whether they have a sense of internal or external control. Externals see themselves as governed by outside forces such as luck or fate. Internals believe they have control over their own lives. Perhaps this latter orientation is more common among patients on home dialysis. See: J.R. Rotter, Personality correlates of survival in a long-term hemodialysis program. Arch. Gen. Psychiat. 22: 566-574, 1970.

When questioned about other aspects of their pre-illness life-style seven of the ten patients on hospital dialysis said that they simply did not have the time or the energy to maintain the same kind of life-style that they had previously known. Those who felt there had been little change in their lives were among the newcomers so it is possible that they hadn't yet had time to assess the full impact of their illness. All of the patients on home dialysis said that their social life was virtually unchanged from what it had been prior to their illness. Four of the transplanted patients reported a change in their social lives - three reported that their social lives were seriously restricted because they were unwell (all were crippled because of bone disease and one was also blind) and because they had financial problems. The fourth said that she was now so busy with the Kidney Patients' Association that she had no time for anything else.

(vi) Patients' Concept of Themselves as Sick or Not Sick

Whether or not a patient views himself as sick is partly dependent upon on how well he is - but other factors, such as attitudes, seem to be important as well. Perhaps treatment modality also had some effect. Twaddle (1969) asked the patients in his study to rate themselves as sick or not sick. The same question was put to the patients in this study with the following results:

Table IV - Patients' Concept of Themselves as Sick or Not Sick by Treatment Modality

TREATMENT MODALITY	PATIENT'S CONCEPT OF SELF		
	Sick	Not Sick	Total
Hospital Dialysis Patients	3	6	9*
Home Dialysis Patients	0	5	5
Transplant Patients	1	5	6*
T O T A L S	4	16	20

*One of the patients on hospital dialysis, and two of the transplanted patients were undecided.

Although the majority of all patients saw themselves as not sick, patients on hospital dialysis were more likely to see themselves as sick. Patients on home dialysis clearly saw themselves as not sick. Six of the eight transplanted patients saw themselves as not sick. Of the patients who were undecided one, who was on hosiptal dialysis, remarked that her freedom was restricted. The two transplant patients, who were both disabled from bone disease, described themselves as "handicapped".

If we look for some common characteristics among the four patients who thought of themselves as sick, we find that three came from families with a genetic history of renal disease - and each of them had seen other family members die. The fourth was of short stature and had grown unknowing that he was "different". All had been under treatment for renal failure for at least three years. All had moved since the onset of their illness. Two were clearly disabled and a third reported that she was unable to do most of her housework. The fourth was relatively well. Two were unemployed, and two were university students who managed to continue their studies but reported that it was a struggle to do so. All four of these patients said that they were too tired or too ill to attend meetings and none were active members in the Kidney Patients' Association. In addition all reported drastic change in their social lives as well.

Thus, although being unwell or feeling sick obviously contributes to an image of oneself as sick, it appears that other factors are also important - particularly in chronic illness. It is possible that some factors, such as growing up in an illness situation, may pre-dispose a patient to acquiesce to his illness. It is also possible that these tendencies are reinforced by treatment programs, such as hospital dialysis which seem to emphasize illness.

K. Career Decisions

Patient careers are characterized by decisions. Sometimes the issues are monumental; sometimes they care rather minor. An example of the latter type occurred when one of the physicians suggested to Betty, a thirty-four year-old farmer's wife, that she undergo a series of daily physiotherapy sessions for bone pain. Betty responded by saying:

> "I can't come right now because we are busy on the farm. I'm needed at home and we can't spare anyone to drive me back and forth. But as soon as the harvest work is done, I'll come." [47]

In another somewhat similar instance, a physician suggested to a young male patient that he eat cookies with a dietary supplement intended to relieve the itching which dialysis caused. Since these cookies are not commercially available they have to be made at home. In this instance, the young man's wife, who was also present, said:

> "Doctor, I've told him that I just don't have time to make those cookies for him but I'll gladly teach him how to do it." [48]

In both of these examples the patient, or his spouse, was clearly indicating that there were times when illness needs had to come second to other family responsibilities. This response contrasted very sharply with those of other patient's or families where the illness always seemed paramount. Terry's family, for example, had apparently abandoned all semblance of normal family life in order to care for Terry. Whatever time or energy his parents, particularly his mother, had to spare was devoted to the Kidney Patients' Association.

---

[47] Betty was one of the patients on home dialysis who was not included in the sub-sample. Field Notes, May 21, 1973.

[48] Field Notes, June 1, 1973.

Decisions of this type illustrate that patients and families exhibited varying degrees of compliance with medical orders and illnes routines. They also suggest that low-level decisions were characterized by a high degre of individuality.

Were high level decisions, such as the choice of treatment modality, also characterized by the same degree of individuality? This question is difficult to answer since few patients could emphatically say how and when their choice was made. If we look, however, at the answer the patients gave when they were asked who took the initiative in suggesting that they learn to run the kidney machine, we find that six of the eight transplant patients could not recall that anyone had done so. This may be because they were on hospital dialysis prior to the big push for home dialysis, or because they resisted all overtures of this nature.

Of the remaining patients, however, six (three on hospital dialysis and three on home dialysis) indicated that the initiative had come from the doctor. Four (one on hospital dialysis, two on home dialysis, and one transplant patient) said that they were first encouraged by a nurse. There is probably a historical trend here - doctors began this move and it was later picked up by the nurses. Another five patients (three on hospital dialysis and one in each of the other modalities) said that they had themselves indicated an interest in learning all about the kidney machine.

The importance of this data is that it indicates that in ten instances the initiative for a career decision came from the staff. In another five cases the initiative came from the patient himself. In no instance were the patient's family nor the other patients credited with suggesting that the patient learn to master his machine.

This pattern appears to be indicative of the decision-making process whereby treatment modalities were selected. In most instances the staff, primarily the doctors, initiated the push for a certain decision. The direction of that push depended upon current medical thinking - and that, of course, varied. The initiative for the decision seldom came from the patient but the final choice was usually the outcome of some sort of interaction between him and the staff. Moreover, staff decisions were usually determined by the physician. There were no observations of instances in which the nursing staff urged the patient to resist a medical decision. The family appeared to play a relatively minor role in the decision-making process.

There were some exceptions, however, with regard to the role of the family. For example, when the patient was a minor, the process which would otherwise take place with the patient more commonly was between doctor and parents. A young girl on hospital dialysis represented another kind of exception where the family was determined that a transplant should be done and offered several possible donors. Apart from that, the family usually supported whatever decision the doctor and the patient had reached.

The important, and somewhat surprising, feature of this data is that the views of the other patients seemed of little import. Although patients did speak with each other about renal disease or treatment, these chats were on a one-to-one basis and not group discussions. Furthermore, not one instance was observed in which one patient tried to persuade another about career choice. In addition, the instance cited earlier in which one patient on hospital dialysis indicated that he had been observing the patients on home dialysis, was rare. Patients seldom indicated that they had been keeping score. And, when they did, they seemed to be very selective. For example,

a patient who wanted a transplant might cite all those patients he knew who had done well, and a patient who opposed transplantation might list all of those he knew who had died. No patient ever indicated that he objectively kept score.

This sort of one-sided score-keeping was not restricted to the patients. The staff seemed to indulge in the same sort of exercise. Apart from the nurses' log, which was a sort of scrap-book of ward events, the staff claimed that they did not keep survival statistics. The doctors indicated that they had some working knowledge of how the unit was faring, and that they could at any time extract statistics from their records, but denied that they kept any accessible record on survival rates.

Thus, although it is possible that both patients and staff evaluated some of the consequences of career decisions, there is no indication that they did so in a scientific manner. While there did appear to be a consensus among staff that favoured home dialysis, there is no evidence of a similar consensus among the patients.

The implications of these findings about career decisions will be elaborated upon in the following chapter.

Chapter V

DISCUSSION

The previous chapter presented a number of findings but made little attempt to explain them. This chapter will discuss the findings and the relevance of the career perspective to renal failure in general and to each treatment modality in particular.

A. Relevance of a Career Perspective to Renal Disease in General

The career perspective has been a useful analytic tool in the study of the disease experience of tuberculosis (T.B.) patients (Roth, 1963). In this section the applicability of this perspective for renal patients in general will be considered.

There are two distinct differences between the careers of renal and T.B. patients. The first is that the careers of T.B. patients as they were outlined by Roth (1963) were primarily institutional careers. The patients dropped out of the normal world, and were immersed in an illness situation, until they re-entered the normal world again. Renal patients do not "drop out" in quite the same way. For this reason the analogies between prisoners and T.B. patients would not be as appropriate with renal patients. The careers of renal patients lie somewhere between the well and the sick world - in much the same way that the prisoner on day parole moves back and forth between the outside and the prison environment. The extent to which the renal patient identifies with the "outside" or the "illness world" is determined in part, by his treatment modality.

The choice of treatment modality represents the second major distinction between T.B. and renal patients. Tubercular patients have individualized

trajectories but for all practical purposes they have only one treatment program. Renal patients also have individualized trajectories but, in addition, they have three treatment choices which may represent three distinct careers. In addition to these two major distinctions, there are a number of other similarities and differences between the careers of renal and tubercular patients.

Most T.B. patients expected to fully recover from their illness. As a group renal patients cannot realistically expect to recover. At the most, they can expect to enjoy recovery for a limited period of time. Roth suggests that the treatment goal, and expectations as to when it may be achieved, affects the patient's concept of time. The T.B. patient is clear about his treatment goal but is uncertain as to when it can be expected. Like the prisoner with an indefinite sentence he comes to view treatment in terms of "putting in his time." If he is being realistic the renal patient is uncertain as to how long he can survive and it is possible that he views treatment in terms of how he can make the best use of the time available to him.

Roth reports that when the T.B. patient first learns of his illness the staff are vague in imparting expectations about the duration of treatment. When limits are given they generally exceed what the staff expect so that the patient will not likely be disappointed at the outcome. Both the observational data and the responses of renal patients in this study suggest that they too are given very vague expectations about treatment and prognosis. Although most renal patients seemed to have some general idea of the seriousness of their disease, neither staff nor patients gave any indication that the prognosis was openly discussed. Such discussions were never observed. If and when they take place it is probably in a private

discussion betwen the patient and his physician.

When the tubercular patient is diagnosed he learns that there are degrees of tubercular involvement and that the length of time he will serve in hospital depends upon the seriousness of his disease. No such parallel exists for the renal patient - at diagnosis he has nothing upon which to gauge his particular prospects. However, just as the T.B. patient learns that he can improve his prospects by co-operating with his treatment regime, so the renal patient learns that he may feel better, and survive longer, if he co-operates with the dialysis routine. In both instances, however, there are elements of response to treatment which are beyond the patient's control.

Once treatment is initiated the T.B. patient has difficulty determining if his progress is on target with his expectations. His progress must be measured by tests and he is dependent upon the doctors to reveal this information to him. The renal patient can more accurately evaluate how he is doing by simply assessing how he feels. When he does want information from the doctor, however, he does not experience the same difficulty as the T.B. patient who has a hard time trying to extract information from the staff. In fact, the renal patient is very readily given test results and is usually encouraged to take an interest in the medical aspects of his care. For example, his vital signs are taken regularly throughout dialysis and he is usually told what they are. He is also usually told about the results of blood tests.

Two very different assumptions seem to be operating here. It seems that it is assumed that T.B. patients might be discouraged or overwhelmed if they were kept informed, whereas informed renal patients are assumed to be more confident and hence more co-operative. The assumptions are not

without a practical basis. The results of the T.B. patient's tests may indicate little change, whereas the renal patient can expect more dramatic fluctuations. Furthermore, the co-operative T.B. patient has a passive role - he simply sits and waits; the co-operative renal patient, on the other hand, plays a much more active role by doing the "right" things and avoiding the "wrong" ones.

Test results determined the rate at which the physicians promoted and demoted the T.B. patients through the stages toward recovery. Renal patients could make two moves which can be viewed as promotion and demotion. Selection for home dialysis was, in a sense, a promotion since it indicated that the doctors thought that the patient was doing well - and could be expected to continue to do well in the foreseeable future. On the other hand, if the initiative for a transplant came from the physician it could be an indication that they felt the patient was not doing well on dialysis and thus represent a demotion.[49]

T.B. patients used a variety of manipulative and persuasive techniques to pressure the doctors into altering the usual pattern of progress through the stages. The sphere of the patient's influence, however, was rather limited and was usually confined to increasing his activities at a faster rate than the physicians would normally allow. The routine which usually governed when decisions of this sort were made was based on what was convenient for the staff and the institution and thus the doctor could alter

---

49 The two transplants done during the course of the study were likely in this category. Both patients were new to the treatment program. One was scheduled to go on peritoneal dialysis at home but she was failing her training program. The other was an Indian woman whose husband refused to relocate the family near the hospital. Home dialysis was out of the question since she lived in a cabin in Northern Alberta. In both instances the transplants seemed to be intitiated by the physicians because they saw no alternative. Field Notes, May and June, 1973.

it without jeopardizing the patient's health.[50] The doctor did, however, run the risk of making life more difficult for himself and his colleagues if all patients demanded individualized programs.

Renal patients had less reason to negotiate with the staff for favours. The major exception could be to pressure for a transplant. In earlier days, when transplants were more common, it is possible that patients who didn't want one had to resist the pressure to consent. At the time of the study, when transplants were not strongly advocated, it is possible that the patient might push to get one. The doctors could be quick to agree if a family donor was available. Those who wanted a cadaver transplant, however, went on a waiting list. Or at least some patients seemed to think that they were on a waiting list.

It is doubtful that such a waiting list really existed. The staff never gave the researcher any indication that it did. When kidneys became available the recipients were selected on the basis of need and the acceptability of the match. However, patients believed that such a list existed and that they would be moved up if they had the misfortune to deteriorate, or the good luck to strike a perfect match.

From the patient's point of view, the waiting list constituted a trust between them and the medical staff. They trusted the doctors to follow the list, or to make exceptions for patients who were doing poorly or for those who happened to be particularly good matches for the available kidneys. Thus a patient could not broach the subject without violating this trust agreement. Since the patient had no alternative sources of medical care, he was understandably reluctant to challenge this trust.

---

50 Roth cites one instance in which a member of the staff developed tuberculosis. She was rushed through the stages more quickly than any other patient. See: J. Roth, Timetables: structuring the passage of time in hospital treatment and other careers. (New York: The Bobbs-Merrill Company, Inc., 1963) p. 32-35.

Furthermore, if the patient initiated the move for an out-of-turn transplant it could mean that he was receiving a favour at the expense of his fellow patients, or that the doctors agreed that he was, in fact, worse off. T.B. patients did not face the same dilemma. Quite the contrary, if they were able to win concessions there was a real possiblity that other patients might also be able to get similar consideration. Thus, a concession for one T.B. patient could establish a precedent which would benefit all.

This trust agreement suited the renal physicians and it was in their best interests to maintain it. That way they could decide who was going to be transplanted, and when, without any fear that they would have to justify their reasons to the other patients. This meant that although both patients and nurses were surprised at the selection of two novice patients who were transplanted during the course of the study, not one person openly challenged it.

This agreement was particularly useful to the doctors at a time when most of them were quietly convinced that cadaver transplantation was too risky except for patients who were doing poorly. If the doctors had been forced to openly admit to this view the patients who were waiting would have been discouraged, and those who were selected would have realized that for them transplantation was viewed as a last resort. Thus, the official policy of transplanting patients according to the list remained, but unofficially the doctors slowed down public appeals for organs so that fewer would be available, and fewer transplants could be done.[51]

---

[51] This change in policy was conceded by the chief renal physician who was asked if enough kidneys were being made available. "That depends on how many you want. We used to get as many as we could, treat rejection as conservatively as possible, and try to keep the kidney. Now we're less anxious to do them - and when we do we are much quicker to pull the kidney in order to save the patient." Field Notes, May 30, 1973.

The other area of negotiation in the renal unit was among patients on hospital dialysis for preferred dialysis schedules. The doctors very wisely left these decisions up to the nurses - on the grounds that they could best decide how the schedules would affect their work load. The preferred schedule was a night run since it allowed the patients to pass the time by sleeping - and thus represented less interference in their daily lives. The second preference was for a schedule that excluded week-ends. Employed patients always got first preference. Beyond that there was an informal pecking order which gave priority to senior patients or those who were not well. Low-ranking patients took whatever was left.[52]

Since decisions about dialysis schedules were generally based on seniority and employment status, the nurses usually had little difficulty justifying them to the patients. Like the staff in the T.B. hospital, however, they made other decisions which seemed like favours and, when these were visible, they were more difficult to justify. The informal credo of independence meant that patients on hospital dialysis were expected to set up their own machines and have everything ready for the nurse to hook them up. They were also expected to assist her in the hooking up process, and when the dialysis was over they were expected to clean-up. These procedures added about an hour to the dialysis routine. Occasionally when a patient was in a hurry, or was not feeling well, the nurses exempted him from these responsibilities. Sometimes friction resulted - especially since the nurses clearly thought that some patients

---

52 One of these, a sixty-year old man who had only been on dialysis for a few months, was noticeably upset and depressed when he was told that he would have to take a Tuesday, Thursday, Saturday schedule. He lived in a farming community just outside of the city. As he pointed out, it had been hard to give up farming but he gradually realized that he was no longer physically able to do much. The social life of his community was one of his few remaining pleasure and week-end runs would mean that he would miss out on many of the important events. "It all makes me wonder," he said, "if it is worth it." Field Notes, June 12, 1973.

were more deserving than others of this kind of consideration.[53]

For the most part the staff attempted to be impartial in dispensing favours. However, like the staff in the T.B. hospital, they occasionally used privileges as rewards and punishments. Nurses were more likely than doctors to use this technique - probably because they had greater opportunity to do so.[54]

There was one unusual incident during this study in which a patient made a request of the doctors. This incident involved a young man on hospital dialysis who requested that an experimental drug be obtained for him from the United States. In this instance the doctors agreed. They may have done so for any of a number of reasons. In the first place, the request was unusual and there was little reason to believe that they would establish a precedent in complying. In addition, this patient was highly unusual in that he was extremely knowledgeable about kidney disease and thus the doctors were accustomed to treating him as a colleague. But he also had an additional advantage in that his parents were always willing to intercede on his behalf. As one nurse put it:

---

53 One of the patients was particularly distraught when she saw others getting what she thought was preferential treatment. This convinced her that the nurses did not like her - and that, in turn, reinforced her tendency towards demanding behaviour. It was only after she holidayed in Europe and was dialyzed under more impersonal conditions, that she came to value the treatment she got at home. Field Notes, May and June, 1973.

54 The propensity of nurses to reward or punish was illustrated one day with Ron - the patient whose transplant had failed after two months. He had a reputation as a difficult patient and he was understandably distraught when he was admitted for dialysis and removal of his kidney. While he was undergoing dialysis a nurse entered the room to ask him what he would like for supper. "I just want a hot dog," he said, "so please stop by the snack shop and get me one." "Ron you know you are not supposed to eat those kinds of things," she said, "maybe your new kidney wouldn't have given you so much trouble if you had watched what you ate." When she left, the researcher asked Ron if transplant patients had dietary restrictions. "I thought not," he said bitterly, "at least everyone had always told me that I could eat what I wanted to. But now people are telling me I shouldn't do this, and I shouldn't do that. It makes me wonder if I'm supposed to feel that it's my fault that the kidney failed." Field Notes, June 15, 1973.

> "We always let Anthony have what he wants. If we don't his mother goes straight to the top. She tells the Administration that she has already lost three children and the remaining three are dying. That never fails to get to them and they always tell us to give in. We know the hassles so we just avoid them by doing what he wants." Field Notes, June 7, 1973.

In other words, patients who wished to negotiate with the staff might have been able to do so more successfully if they had learned from Anthony's experiences. None did so, however, and there was never any indication from Anthony that he was going to share his strategy.[55]

Roth states that T.B. patients were an interacting group and that, in the course of this interaction, they developed a consensus with regard to goals and norms. Observational data from this study suggests that such is not the case with renal patients. Group discussion pertaining to the disease or treatment seldom cocurred. The single most dramatic exception occurred when a patient died. The staff reported that when a death was announced the patients went through a collective exercise in which they attempted to determine the cause of death. Generally they concluded that the patient died of some non-renal disease - or as a consequence of not taking care of himself. In other words the patients reassured themselves that there was no need for them to identify with the patient who had died since he "obviously" did not die of renal failure.[56]

---

[55] The author did, however, note one other instance in which a family member interceded on the patient's behalf. This was an incident in which one of the physicians attempted to persuade a man to have a transplant and his wife foiled the attempt by raising a number of questions about the risk. This particular instance illustrated that fortunate patients could appear compliant and polite if a family member was available to argue for what they really wanted. The end result could be, as it was in this case, that the patient not only got his own way but did so without risk since the staff directed their hostility at his wife. Indeed in this instance the staff even felt sorry for the man because of his "domineering wife." Field Notes, May 18, 1973.

[56] A death occurred during the course of this study but the researcher was not present when the news was broken to the other patients. The staff reported that this is the sort of reaction which ensued - and that this was a common response. Field Notes, June 5, 1973.

This does not mean, however, that renal patients did not discuss the disease or its treatment with one another.[57] As the findings already indicated, patients frequently reported that early in their careers they had met a patient or patients who had exchanged information with them. This generally took place on a one-to-one basis and what the patients tended to offer was their own views or experiences - not reflections of group opinion. The effect of these discussions is difficult to evaluate. One patient reported that another patient had given him an explanation of treatment which was easier to understand than that which the doctor had given him. With two exceptions the patients reported a positive effect from meeting other patients who explained things they had yet to experience. The exceptions were a woman who felt she had been told "all the bad things", and the man who saw another patient convulse.

Roth also states that when a T.B. patient discovered that his career was not following the expected plan that he would select another patient, who was doing much worse, as a reference point. Other sociologists such as Davis (1963) and Glaser and Strauss (1965 and 1968) have made similar observations. There were some indications that renal patients did the same thing. However, it appeared renal patients were more likely to follow this pattern if they were comparing themselves to others in the same modality. On the other hand, when they thought in terms of changing modalities they were more likely to compare themselves to someone who was doing well. Both patients and staff seemed highly selective about the way in

---

[57] The staff on the medical ward indicated that they were aware that naive and experienced patients met on their ward and that such encounters could have both positive and negative consequences. They made no attempt, however, to intervene in these situations. The staff of the dialysis unit sometimes arranged dialysis schedules in order to achieve a certain mix of patients. This was generally done, however, in a way that made management of the patients easier for the staff.

which they kept score on transplantation. It appeared that each endeavoured to reinforce his own view on transplantation by recalling only those experiences which supported it.

Roth bases his case for viewing the experiences of T.B. patients as careers on the fact that there was group interaction which lead to a consensus regarding goals and timetable norms. The indications from this study, however, are that renal patients do not have the same sort of consensus with respect to goals. Career decisions, particularly career choice, seem to be highly individualistic. Timetable norms also appear to be individualistic. There is no indication, for example, that patients felt that after a certain length of time on hospital dialysis they were constrained to make a choice between treatment methods. The consensus about the preference for home dialysis existed only among the staff, and patients seldom complied unless they lived outside of the city. Although there appeared to be both early and late decisions to transplant these too did not seem to be the result of consensus - but rather of two different, and highly individualized, decision-making processes.

There are a number of possible reasons for this apparent lack of consensus among renal patients. The first may be that they simply did not have the same opportunities to interact as did the T.B. patients. It is certainly true that renal patients, who are largely treated on an out-patient basis, do not have the prolonged contact with other patients that T.B. patients have in a tuberculosis hospital. When renal patients had contact with one another it was almost exclusively with patients in the same treatment modality. However, like T.B. patients renal patients could, if they wished, develop avenues to learn about how other patients were. They could, for example, ask the staff or make use of the hospital grapevine. In

addition, they had access to the Kidney Patients' Association which could have been used for this purpose. Since renal patients did not establish an information network we must consider the possibility that they did not want to.

T.B. patients developed their consensus on the basis of what was average or normal. Once they established what the norms were, they displayed little anxiety as long as their progress was within the limits defined by those norms. If they did better they rejoiced in their good luck. In fact Roth cites the example of one patient whose recovery was faster than expected and added that this patient could have pushed for an even earlier discharge by giving up part of his Christmas leave. The patient did not do so because he was already doing better than he expected (Roth, 1963, p. 40). If, however, he seemed to be doing worse than the norm specified, the T.B. patient then experienced anxiety and either had to re-define the norms or view himself as the exception. Roth indicates that most went through some sort of structuring process whereby they re-defined the norms. Often this meant that rather than compare themselves to the T.B. population in general, they compared themselves to a group who had started out with a similar degree of seriousness or who had suffered a similar set-back.

Renal patients, on the other hand, seemed to shy away from developing any consensus as to what was normal or average for patients with renal failure. This is understandable since if they did, they had to admit that their chances for survival were slim. In short, renal patients did not want to be average - they wanted to be the exception. Thus, the less they acknowledged the failures, the more they could continue to believe that they were doing well. For their part, the staff seemed to encourage this kind of perspective. Not only did staff not refer to survival rates when talking to patients, they also seldom referred to them in talking to each other.

Thus, it is highly likely that the process which staff observed when patients were collectively notified of the death of another patient, is indicative of a more generalized process whereby patients dissociated themselves from the experiences of their fellow patients.[58]

The lack of concensus among renal patients with respect to goals and timetable norms mean that although the career perspective is a useful analytical tool, it is clearly limited in that the experiences of renal patients in general do not appear to constitute careers. It is possible, however, that each treatment modality may constitute a career and that the career typology may therefore be of greater value in analyzing the modalities.

B. Relevance of a Career Typology to Each Renal Disease Treatment Modality

In this section we will look at each treatment modality to determine if they are characterized by distinct expectations, goals, and norms.

(i) Hospital Dialysis

Before we look at the group data for patients in this modality, a case history of one of the patients may enhance our appreciation of what it is like to be in this treatment program.

Rebecca is forty-seven years old, married, and has no children. She was born in Switzerland and describes both her childhood and early adulthood as unhappy. Her mother died of renal disease and Rebecca recalls it as a

---

58 The author has noted a similar process among leukemic children. For example, children rarely overtly ask if their disease is fatal. When they do they usually use the third person when phrasing their question. For example, they may ask, "Do people die of this disease?" Of the few who ask this question, fewer still go on to ask "Will I die?" Evidence to date suggests that, despite the cues around them, most children do not generalize from the experience of others to themselves. When this transfer does occur, it happens only when the child is clearly terminally ill.

horrible disease and a horrible death. As a child Rebecca worked on the family farm and later was employed in a watch factory. Much of her salary, however, was used to support her family.

She had resigned herself to remaining single but when Leonard returned from Canada to claim Rebecca's sister as his bride, and the sister rejected him, Rebecca impetuously consented to marry him. She immediately left with him for a new life in Canada.

For a brief while Rebecca thought that all her dreams had come true. At last she had someone to take care of her. She and her husband moved to northern Alberta and she worked to supplement his income and realize their hopes for their new life. Unfortunately, she soon developed renal disease. For a number of years she got steadily worse and was unable to work. The doctors up north offered her no hope and her depression became so profound that she contemplated suicide.

When failure ensued she was sent to Edmonton. Since her English was poor she understood little of what was happening to her. After a long period of time her English improved and she gradually developed a better understanding of the treatment and the fact that her condition was serious, but not hopeless.

Rebecca has been on hospital dialysis for three years. At first she did not want a transplant but now she is getting weary of dialysis and feels that she is ready to take a chance. Her doctor has told her, however, that she has antibodies as a result of her many transfusions and that she must wait for at least another year.

In the meantime, Rebecca feels that she is sick. Although she has no evidence of bone disease or blindness she does not have the energy to work. Her husband does most of the housework and they seldom go out or entertain

friends. Knitting is her only diversion and she sells some of her work to help out financially.

She feels that her life has changed drastically because of her illness. She is bewildered by the recent attempts on the part of the staff to encourage patients to become more independent. In her view, the staff should be "taking care of the patients." On a few occasions when she has asked to be excused from treatment responsibilities she has sensed that the nurses were angry with her for being "a demanding patient". She is extremely upset by this response and has tried to be more cheerful and agreeable. Despite her efforts she never quite succeeds and it is likely that the staff will continue to see her as poorly rehabilitated and thus a treatment failure.

How representative is Rebecca of the patients on hospital dialysis? Of the ten patients currently on hospital dialysis, six seem to have selected it as a career. An analysis of this group reveals that they ranged in age from nineteen to forty-eight years. Three were male and three were female. Four came from families with a genetic history of renal failure and five reported a slow onset of their disease. Five also indicated that they had moved closer to the hospital following the onset of their disease.

Five of these patients were single. Five also reported that they attended church at least once a month. Two had achieved less than high school graduation, and four had education beyond high school. Of the latter, two had university degrees. Four of the patients were "employed", but three of these were university students, so only one was gainfully employed.

All were inactive members of the Kidney Patients' Association, and all reported a high degree of change in their social lives subsequent to their illness. Three saw themselves as "sick", two said they were "not sick", and the one who was undecided saw herself as "restricted". Three of these

patients reported that hospital dialysis was their treatment choice, and three preferred transplantation.

The distinguishing features of this group are the high incidence of genetic etiology, the slow onset, their religiosity and marital status. The fact that many are single means that they are not really eligible for home dialysis. Three would also appear ineligible because of their limited education. The three university students reject home dialysis as inconvenient. The further fact that only one was gainfully employed supports the view that this modality is incompatible with work.

They also have a marked tendency to view themselves as sick or disabled. But, where this latter characteristic is concerned, it is not clear whether this reflects a predisposition to choose hospital dialysis - or is a consequence of the treatment program. The patients in this group do appear, however, to have a set of expectations which may lead them to choose, or permit them to more readily adapt to, a chronic illness routine. They appear very willing, for example, to re-structure their lives around their illness. The fact that they were inactive members of the Kidney Patients' Association, and reported a dramatic decline in their pre-illness social lives, further suggests that their illness had become the focal point of their lives. If religiosity is associated with an external locus of control it may be yet another indication that these patients are inclined to surrender the responsibility for their care to others.

Although they appear split on treatment preference, all of these patients probably wanted a transplant. Some were simply more willing than others to wait until the odds for a successful transplant were better. The most resistant patients were those who were highly educated - but time seemed to have a wearing down effect and senior patients reported that they were less

reluctant to have a transplant than they had once been.

Both staff and patients semed to agree that hospital dialysis was an illness modality and that patients in this group were sick. However, the staff, and some patients, seemed to feel that it was inappropriate to remain here for long. To do so was to remain sick and certainly no patient should want to remain sick. Patients are supposed to want to recover and the nurses, in particular, expressed disappointment over caring for patients who did not get better. Thus the staff encouraged patients to either move out of this modality - or adopt the attitudes and behaviour of other modalities - particularly home dialysis. Patients on hospital dialysis who insisted on being treated like patients were subjected to various sanctions. The most usual response was for staff, particularly nurses, to stifle their sympathetic tendencies because they thought that their traditional caring techniques were not in the patient's best interest. The patient's "best interests" lay in rehabilitation and thus in home dialysis.

(ii) Home Dialysis

The following summary of the case history of Keith will serve to highlight the experiences of patients on home dialysis.

Keith was a twenty-nine year old farmer who had been well until about seven years before when he suddenly began gaining weight because of fluid retention. He went to see his family doctor who immediately admitted him to the local hospital. For three weeks he was treated with drugs and a salt-restricted diet. He was then transferred to Edmonton and placed on dialysis.

He remained on hospital dialysis, usually on a night schedule, for six years until he was offered the opportunity of going on home dialysis.

He immediately accepted. Because he was unmarried two of his brothers offered to be his partners. One brother is now getting married and thus Keith anticipates some problem in maintaining a partner but he feels that there will always be someone who is willing to help.

Keith prefers to dialyze at home. He feels that his background as a farmer has familiarized him with machines and thus the thought of running his own kidney machine doesn't bother him. He also finds it more convenient to dialyze at home. The dietary restrictions do not bother him either. He has a scientific approach to feeding his cattle and finds it easy to take a scientific approach toward his own eating habits.

He says that he has never seriously considered a transplant. As he explains, "the risks are too high and besides I am in good health."

Keith feels that his illness has not made a drastic difference in his life. "All I ever wanted to do was raise cattle and I'm doing it. Besides I never did want to set the world on fire. So I'm happy. I will say, though, that I do appreciate the little things more. I think I take out more time to be grateful that I am alive."

Although the other patients in this modality did not seem to be as philosophical as Keith, they did appear to have a great deal in common. In fact, as a group, they displayed the least variability.

Although they varied with respect to the length of time they had known about their renal problems, these patients were generally asymptomatic at the time of discovery and quickly went into failure. Four were male. Four were married, and with one exception they resided in rural areas. None had moved closer to the hospital. Educationally, they were less scattered than those in other groups - none had less than a grade eight education and none were university graduates. The only unemployed patient was an unemployed

housewife - and her employment status was not related to her illness.

All stated that they did not attend church and, as a group, they expressed little interest in the Kidney Patients' Association. All saw themselves as "not sick". They also reported little change in their social life as a consequence of their illness. What is perhaps surprising is that only three preferred home to hospital dialysis. Two reported that they preferred home to hospital dialysis simply because they lived so far from the hospital that it was more convenient to dialyze at home. (Again it appears that for some patients the choice between hospital and home dialysis is simply one of convenience). Like the patients on hospital dialysis many of those (four of the five) on the home program stated that transplantation was their treatment choice. But many of them also felt that they would wait until they either needed one or the propsects for a successful one were better. As a group these patients seemed slightly more determined to wait than did those on hospital dialysis.

The distinguishing features of this group are their short symptom period, their sex, marital status, similarity in educational backgrounds and employment status, low rating on church attendance, little evidence of change in their lives and their distinct tendency to view themselves as "not sick".

A short symptom period may be related to a tendency to choose a treatment modality which minimizes illness. The fact that these patients are also predominantly male could simply be a reflection of sex-related incidence of renal failure - but it is also possible that there is a bias towards selecting males for this modality, since they may be expected to be more mechanically inclined. Their educational background is probably also important. The fact that the poorly educated are not included in this treatment

group strengthens the conviction that they are not usually selected for home dialysis. The fact that university graduates were not found in this group may be significant, but it is more likely that this is simply a function of the small sample and, given a larger sample, it is likely that university graduates would be found among patients on home dialysis.

Education and marital status are probably reasonable selection criteria, since the training program is demanding and a partner is mandatory. The fact that most are employed suggests that this modality is compatible with employment - and even perhaps that patients choose it so that they can remain employed. Their low rating on religiosity is intriguing and if we apply Rotter's dichotomy (1966), then these people may have an internal sense of control and may thus feel that they are "masters of their fate". Their propensity to be employed, the little evidence of changes in their lives, and their insistence that they are "not sick" is suggestive of a group with a strong sense of self-discipline and a determination to be normal.

In short, home dialysis was viewed as rehabilitation, and the norms associated with it are appropriate to rehabilitation. The patients were expected, and generally did, see themselves as more handicapped than sick and they were expected to integrate their illness routines into their normal lives. Employment was taken as the best single indicator of rehabilitation, although the staff also considered such things as a "normal" home life and the degree of responsibility which the patient assumed for his own care.

(iii) Transplantation

Eleanor, who is a forty-six year old married woman with five boys, represents one of the successful transplant patients. She first developed

renal symptoms when she was thirty-four years of age and pregnant with her fifth child. When she subsequently became pregnant again the doctors terminated her pregnancy. Later she was treated for high blood pressure and then placed on a strict diet. When that failed in 1969 she was sent every 10 days to the hospital in Calgary for peritoneal dialysis. That too wasn't very successful and she found it impossible to wait for ten days between treatments. Finally, the doctors suggested that she come to Edmonton for hemodialysis. She recalls that she was terrified but she was also desperate for treatment. Her memories of the machine are also unpleasant - particularly during the time when she was alone in the city. Her family eventually moved to Edmonton but her condition continued to deteriorate.

She was transplanted in 1971. Here is her description of the events which led to her transplant:

> "I was on the machine in the middle of dialysis when the nurse just came in and unhooked me and said, "you don't need this anymore because you are going for a transplant." And I said that I hadn't come prepared for that, and that I would have to go home and pack my bags, make some arrangements for my children, and telephone my husband who was out of town. I don't remember giving consent, and I certainly don't remember signing anything although my husband may have. On the other hand I knew I was failing. I was down to about ninety pounds and I knew if I didn't get a kidney soon it would be all over. I just couldn't take dialysis much longer. In fact, I remember saying to the doctor, "You've just got to do something."

Although she is not exactly sure how she came to have a transplant, Eleanor certainly has no regrets. Although she thinks home dialysis is great for other patients she doesn't think she could do it. When she was on dialysis she saw herself as sick but now she doesn't. As she put it:

> "I have been re-born. I can do practically anything - even ride a bike. I would go back on dialysis if I had to but I would prefer another transplant."

Eleanor has not been employed since prior to her marriage. Now she spends almost all of her free time working for the Kidney Patients' Association.

As a group, the transplant patients, like the hospital dialysis group, displayed a great deal of variation in a number of areas. Six were male and two were female. Five were married, two divorced, and one was single. The majority of these patients had known for more than ten years that they had a kidney problem, but apart from that there is no identifiable pattern among them with respect to symptom period or the nature of the onset of failure. Five had their tranplants after less than a year on dialysis, and three waited from one to three years. If we separate them into early and late transplants, no distinct characteristics immediately emerge.

These patients are scattered throughout education levels I to IV, but six of the ten had less than a high school education. Five were employed, three unemployed. Five saw themselves as not sick, one said he was sick, and two said they were disabled. Three reported that they had moved closer to the hospital while they were still on dialysis - and none reported such a move subsequent to transplantation. They varied with respect to religiosity, but only three indicated that they regularly attended church. As a group they expressed the greatest interest in the Kidney Patients' Association - but only five were members, and of these, only three were active. Most of them said that they enjoyed the same kind of social life which they had known prior to becoming ill. Those who didn't stated that they were limited either because of disability or financial problems. All said that transplantation was the treatment of their choice.

Perhaps the most obvious distinguishing feature about this group is the fact that they are not very homogeneous. If we look at those areas

with the greatest degre of similarity, however, the fact that most are male may reflect a sex-linked propensity to be transplanted, or to survive following transplantation, but it is more likely that this is simply related to the incidence of kidney failure. The unmarried are probably more likely to be in this group or the hospital dialysis group and this reinforces the view that a spouse is almost a pre-requisite for home dialysis. Most transplant patients are not well-educated and that suggests that the well-educated are more reticent about transplantation. In fact, a large sample might show distinct differences between those who press for early transplantation and those who subsequently agree because of complications - with the poorly educated being heavily represented in the first group.

Employment and self-image as sick or not sick seem to be directly related to health - with those who are well seeing themselves as "not sick". Again, those who are well also are more inclined to resume their pre-illness life-style. As a group they displayed the greatest interest in the Kidney Patients' Association - but again those who were active members were also well. (Those who were well but inactive lived outside of the city and reported that it was inconvenient for them to actively participate). Perhaps then these patients are excused from the obligation to do good deeds for other patients if they are unwell or live far away from the hospital.

Transplantation is a recovery modality. Patients were expected to view themselves as having been sick - but no longer sick. The fact that this state of well-being was likely only temporary was largely ignored. Perhaps the fact that this modality was viewed as recovery explains why staff and patients alike seemed uncomfortable with partial recovery (where patients continued to have bone disease or developed it subsequent to

transplantation), and why patients seemed to feel that they had a debt to pay. This expectation regarding payment is appropriate to the traditional patient-healer relationship where the patient pays the healer for his services. It would be interesting to know if the expectation differs from among those who have received live transplants and those who have received cadaver kidneys. Perhaps the former feel indebted to the donor while the latter generalize to other patients or to society.

C. Conclusions

What do these findings mean? Because the samples are small, the answer is speculative. However, the data do suggest that all, or almost all, papatients really want a transplant. In others words, they want to recover. The odds for a successful transplant are slim, however, and hence recovery represents a long-term goal. (A small number of patients also viewed some of the consequences of immune-suppressive therapy - most notably the effects of cortisone - as a further drawback to transplantation). Survival is a more immediate goal - and many patients recognize that they are more likely to survive if they wait until the odds for a successful transplant are in their favour.

Some patients, however, are not content to wait. From the very beginning they want a transplant. If they have a family member who can, and is willing to donate, they may quickly have a transplant. If they must go on the waiting list for a cadaver kidney, they may subtly pressure the doctor. Indications are that pressure tactics are rare. It is more common for the patient to express his desire to be transplanted and then expect to take his place on the waiting list. There appears to be a norm regarding waiting time for a cadaver kidney, and most expect to wait for one year until their turn

comes up. However, they also expect to be transplanted earlier if a good match comes up, or later if it does not. It is rare for a patient to ask to be moved up on the waiting list and such negotiations do not take place in the presence of other patients. What the patient may do, however, is indicate that he is not as fussy about the perfect match as he once was.

The findings suggested that there may be a difference between early and late decisions to be transplanted. Late decisions were associated with long experiences on dialysis and almost all senior dialysis patients indicated that their resistance to transplantation was wearing thin. Poor health facilitated this kind of decision.

But what distinguishes the patients who want an immediate transplant from those who wish to postpone it? The single most important criteria is probably social class. As Moore (1970) noted, people from a low socio-economic background are likely to select occupational goals which provide immediate gratification. When people from this background become patients, it seems reasonable to assume that they may choose similar goals in their patient careers. Although this explanation is somewhat speculative it is not negated by the findings in this study and is substantiated by previous research. Some early studies on adaptation to long-term dialysis suggested that indigent patients did not do as well as those from the middle and upper class. For example, Retan et al (1966) stated that dialysis seemed unacceptable to indigent patients and that motivation, intelligence, emotional stability and "rehabilitation potential" were necessary to obtain the degree of cooperation required for long-term success. They neatly skirted the issue of screening, however, by saying that it was "up to society" to determine who should be treated.

Schupak et al (1967) who, like Retan and his colleagues, treated an

unselected group of patients came to a similar conclusion. They felt, however, that motivation and family support were more important than intelligence per se. This early research suggests that the use of social class, however it was measured, as a screening criteria grew out of early experiences in which disadvantaged patients did not tolerate long-term dialysis. This same sort of observation led more recent practitioners to offer only transplantation to patients from low socio-economic groups. Rosenberg et al (1974) describe one such program in which indigent blacks all receive cadaver transplants. According to the authors this method was selected because experience had demonstrated that patients from this background did not do well on dialysis.

By "doing well" the authors seem to mean following medical routine, and becoming rehabilitated. Rehabilitation, in turn, is defined by individual stability, maintaining family relationships, and, above all, being employed. (Patients who did not "do well" however, often died and the authors seemed to feel that it was primarily due to adjustment problems).

Of course, there is a real possibility that this observation about the relationship between class and adjustment to dialysis is not valid, but Safilios Rothschild's (1970) review of rehabilitation lends support to the view that lower class patients find rehabilitation difficult to achieve. The problem, as she saw it, was that lower class patients did not share the same goals - particularly with respect to work and had fewer resources to use in attaining them.[59]

---

[59] It is interesting to note that those who see underprivileged patients as poor candidates for dialysis, viewed renal treatment as rehabilitation and concluded that the problem is not that these patients are impossible to rehabilitate, but only that professionals haven't yet developed the skills to successfully rehabilitate them. In other words, they shifted the blame from the patients to the staff. This is a laudable sentiment which seems a little insincere and probably reflects the author's reluctance to make moral pronouncements regarding class characteristics.

What is it about class that is important to rehabilitation? Unfortunately, class is not a unidimensional variable and so that question is difficult to answer. This study suggests that education is important. As far as kidney patients are concerned, it may simply mean that better educated patients have a more sophisticated understanding of the risks involved in transplantation but it probably goes deeper than that. Values which emphasize health, productivity, employment, self-discipline and self-determination are associated with the middle and upper class - and likely also lead the patient both to postpone transplantation and tolerate dialysis - particularly home dialysis.[60]

If staff and patients always agreed on goals and norms, and patients were always suited to the modality they were in, few problems would arise. But the selection process was not perfect. And for that reason there were always misfits in each modality. Convenience (which is defined by distance from the hospital) was the major criteria for selecting patients for home dialysis. Thus, some patients chose home dialysis for that reason alone, and some patients who appeared to be good candidates for home dialysis found it more convenient to dialyze at the hospital. Health problems sometimes intervened and necessitated a transplant - and some transplanted kidneys were rejected and then the recipient was sent back to dialysis.

---

60 This observation is difficult to reconcile with the fact that many of the doctors and nurses stated that they would choose transplantation for themselves. However, since these were answers to theoretical situations, and many of the staff clearly indicated that they had not thought about personal choice, we should not accept them as indicators of the choice they would actually make. What the staff seemed to be saying when they chose transplantation was that they recognized dialysis as an arduous routine and didn't know if they could "take it." We should also not overlook the fact that many felt that home dialysis was the rational choice and the one that was in the patient's best interests.

Still, even if a patient was suited to his modality, some strain could arise. Norms are often very subtle and the difference between acceptable and unacceptable behaviour is often a matter of degree. Patients could be over-zealous in subscribing to the norms of their modality. For example, patients could be too eager to behave as if they were sick, and also too willing to behave as if they were well.

Roth's (1963) framework for patient careers does not take into consideration pre-illness factors, nor does it provide for variation in the degree to which norms are internalized. Individual variation is not explained by this perspective - nor does it allow for consideration of the way in which an illness career impinges upon the non-illness aspects of the patient's life.

The framework could be expanded to include pre-illness factors relevant to the development of career expectations. This approach would be consistent with the career perspective as it is applied to occupations. It is also possible that this framework could include measures of the degree to which norms are internalized. But the career perspective, by its very nature, implies a high degree of consensus and makes little allowance for individual variation.

Some variations may be explained by the fact that there may be careers within careers. For example, our understanding of medicine as a career is based upon the profession in general - but it is refined when we view each speciality as a separate career. So, too, our understanding of renal careers increased when each modality was viewed as a distinct career. Since each modality is characterized by distinct goals and norms, it seems appropriate to view each as a career. That still leaves us, however, with a need for measures of variation within careers.

Despite its limitations the patient career perspective was a useful tool for examining the experiences of renal patients. The fact that it is not always appropriate should not detract from its value. A tool, such as this one, is also useful if it points out areas where it doesn't fit. This study indicates that the career typology is of value but also that other areas of renal failure should also be further explored.

D. Further Areas of Research

As the literature review indicated, renal failure could be examined from a number of vantage points. Unfortunately, most of them lie outside the scope of this work. Both practically and theoretically the pursuit of professionalization within renal units is one of the most intriguing questions which was left untouched. Within that area there are two questions. The first pertains to staff. The strivings of renal physicians, nurses, and technicians, should receive continuing study. The possibility of the professional patient is another topic that deserves to capture sociological attention. That subject has merit in its own right - but it would also increase our understanding of other facets of patient behaviour.

Patient behaviour has frequently been studied but our understanding of this area is still limited. We know all too little about the illness behaviour associated with chronic disease, and still less about that associated with life-threatening illnesses. At the moment, this kind of illness situation seems to be beyond the realm of our understanding of both chronic disease and thanatology. That is unfortunate for a number of reasons - but most particularly because as medical frontiers expand we can expect to encounter this kind of situation much more frequently.

Certainly, research on the sick role should be revitalized. This area is central to medical sociology and our current impasse is highly regrettable. If we can clearly distinguish between acute and chronic illness roles, we may explain some of the diverse findings and thus make further progress. Within the sick role typology we should take a closer look at acceptance and rejection of the sick role. This study suggested that of the patients who remained on hospital dialysis some did so because it was simply more convenient than home dialysis. Some, however, appeared to like it there - or perhaps, more correctly, appeared to welcome the secondary gains which they associated with an illness modality. The patients who wanted to stay on hospital dialysis had two distinguishing features. First, they were likely to have grown up with some forewarning (either because renal failure was common in their family or because they seemed unhealthy and "different"), and second, their own disease had a gradual onset. It is likely that illness, and an illness routine, seem less traumatic, and may even be welcomed by those who have gradually come to view themselves as ill.

This image of oneself as chronically ill is probably very gradually integrated into the other more general aspects of self-concept. Thus, the patient who suddenly and unexpectedly finds himself chronically ill must quickly restructre his self-image - whereas the patient who slowly progresses to this stage probably finds that he has already come to view himself as sick and has re-arranged his life accordingly. This view of the process of the awareness of oneself as sick is consistent with that posited for the awareness of dying. More recent work in that area, such as Weisman's (1972) treatise on denial, suggests that denial is essentially a healthy mechanism which regulates the process by which reality is recognized.

- and ensures that a painful reality is accepted in gradual stages.

The awareness process associated with illness, like the one associated with dying, is probably strongly related to well-being, and the simple ability to function within the normal roles. However, the process is probably further facilitated by a number of psychological and sociological variables. An external locus of control (which is probably related to religion but more characteristic of some denominations than others) probably enhances the process. Value systems which esteem health, productivity, work, etc. are likely to mitigate against it. Generally speaking, the factors which nurture the tendency to see oneself as sick are commonly associated with low socio-economic status, and those which have some countervailing effect are more characteristic of the middle and upper class. Just as class is not a uni-dimensional variable, so it is also unlikely to have a uni-directional effect. Britt (1975) examined the age-old question as to whether lower class status led to illness, or whether illness was likely to produce lower class status, and concluded that it is probable that there is a reciprocal effect between the two.

There is, then, a real possiblity that pre-illness factors predispose a patient to accept or reject the sick role - and that these are strongly related to class. It is also possible that the nature of the illness or the treatment modality has a reinforcing effect. Illness modalities, such as hospital dialysis, would reinforce a predisposition to accept a sick role; rehabilitation and recovery modalities would reinforce a predispostion to reject the sick role.

Acceptance and rejection of the sick role are two very distinct but broad classifications of the sick role. They are potentially useful, but they need to be refined. Kassebaum and Baumann (1965) isolated four dimensions

of the chronic sick role-dependency, denial, reciprocity and role performance and attempted to measure them. In a slightly different approach Klemmack et al (1974) undertook to measure life satisfaction, social isolation, and the willingness to live. Both studies indicate that further work needs to be done to isolate and measure the various characteristics associated with "acceptance" and "rejection".

Rehabilitation should also receive further attention. This study suggests that home dialysis was a rehabilitation modality and that it attracted patients who were well educated and highly motivated to normalize. This appears to contradict the findings of Ludwig and Adams (1968) who concluded that that rehabilitant's role is in subjugation to the medical expert and that, therefore, success was more likely among patients who were accustomed to submissive roles, or whose social position places them in a status of dependency or subordination. At first the diverse findings are difficult to reconcile. Upon further consideration, however, the two studies are looking at two entirely different rehabilitation processes. For the most part, the subjects which Ludwig and Adams were studying were re-learning very basis tasks - eating, dressing, etc., whereas the candidates for home dialysis were learning a new and complex task which, in a sense, made them equals to their care-takers. Furthermore, Ludwig and Adams ignored the possiblity of postponed gratification. They assumed that patients who were accustomed to be submissive - that is those from lower socio-economic backgrounds, minority social groups, or women, would be more accustomed to being submissive and therefore more amenable to rehabilitation. This assumption does not allow for those who are accustomed to enduring prolonged periods of submissiveness in order to achieve long-range goals. Contradictions and inconsistencies exist throughout the work on rehabilitation

and it is evident that further work needs to be done.

Stress is another area that needs clarification. It was suggested early in this work that a patient's choice of treatment modality may reflect his preference for stress situations. This idea should be tested. In addition we should examine the response of the family as well as the patient. Both the importance of the family in mediating stress upon the patient, and the impact of stress upon various members of the family, and the family unit, should be examined.

The perspective used in this research - the career typology, should also be subjected to further testing. There are, for instance, several reasons why the findings in this particular study should be qualified. The first lies with the small sample and the further fact that it was drawn from one renal unit. The spatial and temporal limits deserve emphasis. There is reason to believe that renal units differ greatly from one another - and that each varies over time. Time is particularly crucial because we were dealing with a new technology and the state of that technology undoubtedly affected the findings. As Rosengren and Lefton (1969) point out, the goals of an institution are related to the technological possibilities and, as the technology improves, the goals and norms can be expected to change accordingly.

The conclusion that almost all patients want a transplant, and that some patients select dialysis as a waiting modality, is consistent with the data, but should be verified by additional research. Social class was posited as the major determining factor between those who choose to wait and those who don't. This explanation is consistent with the findings in this study and the results of other research, but remains speculative. A large sample, and a very precise measure of class, will be necessary to test this hypothesis. Furthermore, class is a very complex variable and although

education appears to be an important factor; it is not at all certain which of the various dimensions of class may be responsible for this effect, nor what kind of causal relationship is involved.

In short, renal failure offers social scientists a rich opportunity to pursue a number of questions which are relevant to their discipline. If they chose to accept the challenge they can provide some answers to pressing practical problems and enrich many areas of sociological theory.

BIBLIOGRAPHY

ABRAM, H.S. The psychiatrist, the treatment of chronic renal failure, and the prolongation of life. I. Amer. J. Psychiat. 124: 45-52, 1968.

ANDERSON, T.R., ZELDITCH, M. A Basic Course in Statistics with Sociological Applications. Toronto: Holt, Rinehart and Winston, Inc., 1968.

A PATIENT'S BILL OF RIGHTS. J. Ren. Tech. 3: 53, 1974.

ANTHONY, J.H., GOODMAN, H.P. The source of health care problems for the urban poor. Mich. Med. 71: 640-644, 1972.

APPLE, D. How laymen define illness. J. Health & Hum. Behav. 1: 219-265, 1960.

BAILEY, G., MOCELIN, A.J., HAMPERS, C., MERILL, J.P. Adaptation of spouse pairs to home dialysis. J. Ren. Tech. 72: 26-46, 1972.

BLACKWELL, B. Upper middle-class expectations about entering the sick role for physical and psychiatric dysfunctions. J. Health & Soc. Behav. 8: 83-95, 1967.

BRAND, L., KOMORITA, N. Adapting to long term hemodialysis. Amer. J. Nurs. 66: 1778-1781, 1966.

BRINKLEY, L.S. Nursing. J. Ren. Tech. 3: 58, 1974.

BRITT, D. Social class and the sick role: examining the issue of mutual influence. J. Health & Soc. Behav. 16(2): 178-182, 1975.

CAIN, L.P. Casework with kidney transplant patients. Social Work 18: 76-83, 1973.

CAMPBELL, D.R., SINHA, B.K. Psychotherapy and hemodialysis. Unpublished paper. University of Alberta Hospital, 1972.

CANADIAN DIALYSIS REGISTER: patients on dialysis in 1973. Health Division, Statistics Canada. In press, 1974.

CONVERSE, J.M., CASSON, P.R. The historical background of transplantation. In: Human Transplantation. Edited by F.T. Rapaport and J. Dausett. New York: Grune and Stratton, 1968. pp. 3-10.

CRAMMOND, W.A. Renal homotransplantation: some observations on recipients and donors. Brit. J. Psychiat. 113: 1223-1230, 1967.

CRAMMOND, W.A., COURT, J.H., HIGGINS, B.A., KNIGHT, P.R., LAWRENCE, J.R. Psychological screening of potential donors in a renal homotransplantation programme. Brit. J. Psychiat. 113: 1213-1221, 1967.

CRAMMOND, W.A., KNIGHT, P.R., LAWRENCE, J.R. The psychiatric contribution to a renal unit undertaking chronic hemodialysis and renal homotransplantation. Brit. J. Psychiat. 113: 1201-1212, 1966.

CUMMINGS, J.W. Feelings, facts and fantasies: the pressures and how patients respond. Amer. J. Nurs. 70: 70-76, 1970.

DAVIS, F. Passage Through Crisis: polio victims and their families. New York: Bobbs-Merrill, 1963.

DOSSETOR, J.B. Present status of renal transplantation. Can. Nurse 63: 32-34, 1967.

DURKHEIM, E. Suicide: a study in sociology. Translated by John A. Spaulding and George Simpson. Glencoe, Illinois: The Free Press, 1951.

ETZIONI, A. (ed.) The semi-professions and their organization: teachers, nurses, social workers. Toronto: Collier-Macmillan, Ltd., 1969.

FARQUHARSON, A. Peers as Helpers: Personal Changes in Members of Self-Help Groups. Unpublished doctoral thesis. University of Toronto, 1975.

FELLOWS, B. Hemodialysis at home. Amer. J. Nurs. 66: 1775-1778, 1966.

FOX, R. Experiment Perilous. Glencoe, Illinois: The Free Press, 1959.

_____ A sociological perspective on organ transplant and hemodialysis. Ann. N.Y. Acad. Sci. 69: 406-428, 1970.

FOX, R., SWAZEY, J. The Courage to Fail. Chicago, Illinois: University of Chicago Press, 1974.

FREEMAN, R., MAHER, J., SCHREINER, G. Hemodialysis for chronic renal failure. I. technical considerations. Ann. Intern. Med. 62: 519-534, 1965.

GLASER, B., STRAUSS, A. Awareness of Dying. Chicago: Aldine Publishing Co., 1965.

_____ Time for Dying. Chicago: Aldine Publishing Co., 1968.

GOFFMAN, E. Stigma: notes on the management of spoiled identity. Englewood Cliffs, New Jersey: Prentice-Hall, Inc., 1963.

GOLDMEIR, J. The social worker. J. Ren. Tech. 2: 10-15, 1973.

GOLDSTEIN, B., DOMMERMUTH, P. The sick role cycle: an approach to medical sociology. Soc. & Soc. Research 61: 36-47, 1961.

GORDON, G. Role Theory and Illness: a sociological perspective. New Haven, Conn.: College and University Press, 1966.

GREEN, C.R. Medical care for underprivileged populations. N. Engl. J. Med. 282: 1187-1193, 1970.

HAMBURGER, J., CROSNIER, J. Moral and ethical problems in transplantation. In: Human Transplantation. Edited by F.T. Rapaport and J. Dausett. New York: Grune and Stratton, 1968. pp. 37-43.

HAMOVITCH, M.G. The Parent and the Fatally Ill Child. Los Angeles: Delmar Publishing Co., 1964.

HASSETT, M. Teaching hemodialysis to the family unit. Nursing Clinics of North America 7: 349-362, 1972.

HICKEY, K.M. Impact of kidney disease on patient, family and society. Social Case Work 53: 391-398, 1972.

HOLLINGSHEAD, A., REDLICH, F. Social Class and Mental Illness. New York: John Wiley and Sons, Inc., 1958.

JOHNSON, M.M., MARTIN, H.W. A sociological analysis of the nurse role. Amer. J. Nurs. 58: 373-377, 1968.

KAPLAN, D., SMITH, A., GROBSTEIN, R. Family mediation of stress. Social Work 63: 60-69, 1973.

KAPLAN-DENOUR, A., CZAZCKES, J.W. Emotional reactions of the medical team in a chronic dialysis unit. Lancet 2: 987-991, 1968.

KAPLAN-DENOUR, A., SHALTIEL, J., CZAZCKES, J.W. Emotional reactions of patients on chronic hemodialysis. Psychosom. Med. 30: 521-533, 1968.

KASSEBAUM, A., BAUMANN, B. Dimensions of the sick role in chronic illness. J. Health & Soc. Behav. 6: 16-27, 1965.

KELLEY, J.T. A legal look at hemodialysis. J. Ren. Tech. 2: 30-31, 1973.

KEMPH, J.P. Renal failure, artificial kidney and kidney transplant. Amer. J. Psychiat. 122: 1270-1274, 1965-66.

_____ Psychotherapy with patients receiving kidney transplant. Amer. J. Psychiat. 124: 623-629, 1967.

KELMMACK, D., CARLSON, J., EDWARDS, J. Measures of well-being: an empirical and critical assessment. J. Health & Soc. Behav. 15 (13): 267-270, 1974.

KOOS, E. The Health of Regionville. New York: Hafner Publishing Co., 1967.

KUBLER-ROSS, E. On Death and Dying. New York: Macmillan Publishing Co., Inc., 1969.

KUTNER, B., GORDON, B. Seeking care for cancer. J. Health & Hum.. Behav. 2: 171-178, 196.

LICHON, M.M., MORITA, Y., PIERCE, J., ROSENBERG, J.C. Sociological aspects at a municipal of cadaver transplantation. Mich. Med. 70: 901-905, 1971.

LITMAN, T. The influence of self concept and life orientation factors in rehabilitation of the orthopedically disabled. J. Health & Hum. Behav. 10: 125-133, 1969.

LOWENTHAL, D.T., GELFAND, G., RAKOWSKI, T., BRIGGS, W.A., CIRKSENA, W.J., SIEGEL, L., KNEPSHIELD, J.H. Who needs dialysis? J. Ren. Tech. 2: 33-36, 1973.

LUDDY, E. Bridging the gap between dialysis and transplantation. J. Ren. Tech. 2: 18-20, 1973.

LUDWIG, E., ADAMS, S. Patient co-operation in a rehabilitation centre: assumption of the client role. J. of Health & Soc. Behav. 8: 328-336, 1968.

MACDONALD, J. Nursing care in renal transplantation. Can. Nurse 63: 35-39, 1967.

MACNAMARA, M. Psychosocial problems in a renal unit. Brit. J. Psychiat. 113: 1231-1236, 1967.

MAUSS, M. The Gift. Translated by I. Cunnison. Glencoe, Illinois: The Free Press, 1954.

MECHANIC, D. The sociology of medicine: viewpoints and perspectives. J. Health & Hum. Behav. 7: 237-248, 1966.

MOORE, F.D. Therapeutic innovation: ethical boundaries in the initial clinical trials of new drugs and surgical procedures. In: Ethical Aspects of Experimentation with Human Beings. Daedalus. 98: 502-522, 1969.

MOORE, W.E. The Professions: roles and rules. New York: Russel Sage Foundation, 1970.

MURRAY, J.E., BARNES, B.A. The world-wide status of kidney transplantation. In: Human Transplantation. Edited by F.T. Rapaport and J. Dausett. New York: Grune and Stratton, 1968. pp. 15-60.

NESBITT, L. Nursing the patient on long term hemodialysis. Can. Nurse 63: 40-41, 1967.

OPEN FORUM: dialysis technician certification. J. Ren. Tech. 2(2): 10-32, 1973.

OPEN FORUM: peritoneal dialysis. J. Ren. Tech. 2(4): 10-17, 1973.

OPEN FORUM: What is the role of the physician in dialysis? J. Ren. Tech. 3(2): 16-47, 1974.

OPEN FORUM: a twenty year perspective. J. Ren. Tech. 3(3): 36-49, 1974.

PARSONS, T. The Social System. Glencoe, Ill.: The Free Press, 1951.

_____ Definitions of health and illness in the light of American values and social structure. In: Patients, Physicians, and Illness. Edited by E. Gartley Jaco. Toronto: Collier Macmillan, Canada, Ltd., 1972. pp. 107-127.

PAUL, B. (ed.) Health, Culture and Community. New York: Russell Sage Foundation, 1955.

PFLANZ, M., ROHDE, J. Illness: deviant behaviour and conformity. Soc. Sc. & Med. 4: 645-653, 1970.

PITTARD, J. Self-care dialysis: further experiences from Olive View Medical Centre. J. Ren. Tech. 3: 18-47, 1974.

RAE, A. Hemodialysis in the home. J.A.M.A. 206: 92-96, 1968.

RAE, A., CRAIG, P. Home dialysis: its costs and problems in medical practice. Can. Med. Assoc. J. 106: 1307-1318, 1972.

RENAL PHYSICIANS' ASSOCIATION. J. Ren. Tech. 3(2): 45, 1974.

RETAN, W.J., LEWIS, H.Y. Repeated dialysis of indigent patients for chronic renal failure. Ann. Intern. Med. 64: 284-292, 1966.

RODRIGUEZ, D.B. Moral issues in hemodialysis and renal transplantation. Nursing Forum 10: 201-219, 1971.

ROEMER, M. (ed.) Henry E. Sigerist on the Sociology of Illness. New York: M.D. Publications, Inc., 1960.

ROSENBERG, J.C., FERRER, G., KLEIN , S., ROELLIG, S. Health practice group. J. Ren. Tech. 3(1): 20-23, 1974.

ROSENGREN, W., LEFTON, M. Hospitals and Patients. New York: Atherton Press, 1969.

ROSS, J. Social class and medical care. J. Health & Hum. Behav. 3: 35-40, 1962.

ROTH, J. Timetables: structuring the passage of time in hospital treatment and other careers. New York: The Bobbs-Merrill Co., Inc., 1963.

ROTTER, J.B. Generalized expectancies for internal versus external control of reinforcement. Psychol. Monog. 80: 1-28, 1966.

SAFILIOS-ROTHSCHILD, C. The Sociology and Social Psychology of Disability and Rehabilitation. New York: Random House, 1970.

SAMPSON, T. Home Training: transversing the maze. J. Ren. Tech. 3(3): 20-28, 1974.

SAND, P., LIVINGSTON, G., WRIGHT, R. Psychological assessment of candidates for a hemodialysis program. Ann. Intern. Med. 64: 602-610, 1965.

SAUNDERS, L. Cultural Differences and Medical Care. New York: Russell Sage Foundation, 1954.

SCHLOTTER, L. Why A.A.N.N.T.? J. Ren. Tech. 2: 46-47, 1973.

SCHREINER, G. Mental and personality changes in the uremic syndrome. Med. Ann. D.C. 28: 316-324, 1959.

SCHREINER, G., MAHER, J. Hemodialysis for chronic renal failure. III. Medical, moral and ethical, and socio-economic problems. Ann. Intern. Med. 62: 551-557, 1965.

SCHUPAK, E., SULLIVAN, J.F., LEE, D.Y. Chronic hemodialysis in unselected patients. Ann. Intern. Med. 67: 708-717, 1967.

SCOTT, R., HOWARD, A. Models of stress. In: Social Stress. Edited by S. Levine and N. Scotch. Chicago: Aldine Publishing Co., 1970. pp. 259-278.

SCRIBNER, B., BURI, R., CANER, J., HEGSTROM, R., BURNELL, J. The treatment of chronic uremia by means of intermittent dialysis: a preliminary report. Trans. Amer. Soc. Artif. Intern. Organs 6: 114-122, 1960.

SHAMBAUGH, P.W., HAMPERS, C.L., BAILEY, G.L., SYNDER, D., MERRILL, J.P. Hemodialysis in the home: emotional impact on the spouse. Trans. Amer. Soc. Artif. Int. Organs 13: 41-45, 1969.

SHEA, E., BOGDAN, D.F., FREEMAN, R.B., SCHREINER, G.E., Hemodialysis for chronic renal failure. IV. Psychological considerations. Ann. Intern. Med. 62: 558-563, 1965.

SORENSEN, G. Dependency: a factor in nursing care. Amer. J. Nurs. 66: 1762-1763, 1966.

SUCHMAN, E. Sociomedical variations among ethnic groups. Amer. J. Soc. 80: 319-331, 1965.

_____ Social patterns of illness and medical care. J. Health & Hum. Behav. 6: 2-16, 1965.

_____ Stages of illness and medical care. J. Health & Hum. Behav. 6: 114-128, 1965.

TAGLIACOZZO, D., MAUKSCH, H. The patient's view of the patient's role. In: Patients, Physicians and Illness. Edited by E. Gartly Jaco. Toronto: Collier Macmillan, Canada, Ltd., 1972. pp. 172-185.

TAYLOR, G. Chronic renal failure, home dialysis, and the liaison psychiatrist. Can. Med. Assoc. J. 106: 1318-1320, 1972.

TECHNICIAN CERTIFICATION. J. Ren. Tech. 2: 10-32, 1973.

TUCKMAN, A.J. Brief psychotherapy and hemodialysis. Arch. Gen. Psychiat. 23: 65-69, 1969.

TWADDLE, A. Health decisions and sick role variations and exploration. J. Health & Soc. Behav. 10: 105-115, 1969.

VINCENZO, B., MASTRANGELO, J. 4 hour dialysis: socio-economic aspects. J. Ren. Tech. 3(2): 34-40, 1974.

WEISMAN, A. On Dying and Denying: a psychiatric study of terminality. New York: Behavioural Publications, Inc., 1972.

WHATLEY, L. Social work with potential donors for renal transplants. Social Casework 63: 399-403, 1972.

WHIPPLE, E. Team approach to chronic hemodialysis. J. Ren. Tech. 1: 42-43, 1972.

WRIGHT, R., SAND, P., LIVINGSTON, G. Psychological stress during hemodialysis for chronic renal failure. Ann. Intern. Med. 64: 611-621, 1966.

APPENDICES

INTERVIEW SCHEDULES

1. Interview Questionnaire for Patients
2. Interview Questionnaire for Nurses
3. Interview Questionnaire for Physicians

RENAL UNIT STUDY

QUESTIONNAIRE FOR PATIENTS

SUBJECT NUMBER: _____

I. BACKGROUND INFORMATION

AGE:

SEX:

MARITAL STATUS:

If married, are there any children?

RELIGION:

Is religion important to you? In an average month, approximately how often do you go to church?

EDUCATION:

OCCUPATION:

Have you changed jobs because of your renal disease?

EMPLOYMENT STATUS: (Employed or Unemployed)

ADDRESS:

Have you moved since you developed renal disease?

Are you, or have you been, active in the Kidney Patients' Association or the Kidney Foundation?

Do you belong to any other clubs and associations?

II. CAREER

How long have you had renal disease?

How did you first learn you had renal disease?

After you learned you had renal disease, how long was it until your first dialysis? Peritoneal or hemodialysis?

Do you remember your first dialysis experience?

How did you learn about the kidney machine? Can you operate it yourself?

How long have you been, or were you, on dialysis?

Current method of treatment:

- dialysis (home or hospital)
- transplant

III. TREATMENT PREFERENCE AND CHOICE

Which method of treatment do you prefer for yourself? Why?

If you are running at home, who is your partner? If you were to run at home, who would be your partner?

IV. CONSEQUENCES OF CHOICE

Approximately how many hospital admissions have you had in the last year?

Do you consider yourself to be sick or not sick?

Is there anything else you would like to tell me?

RENAL UNIT STUDY-

QUESTIONNAIRE FOR NURSES

I. BACKGROUND INFORMATION

AGE:

SEX:

MARITAL STATUS:

If married, are there any children?

EDUCATION: (basic program plus any additional education)

WORK EXPERIENCE:

Where have you previously worked as a nurse and for how long?

How long have you been working on MP-5?

II. VIEWS ON NURSING CARE IN A RENAL UNIT

What is the role of the nurse on MP-5?

Should a nurse on MP-5 encourage patients to be independent? Why?

Is it important for renal patients to learn how to run the kidney machine? Why?

III. TREATMENT PREFERENCE

What type of treatment-hospital dialysis, home dialysis, or transplantation do you think is best for patients? Why?

If you were a patient, which treatment would you select for yourself? Why?

RENAL UNIT STUDY

QUESTIONNAIRE FOR PHYSICIANS

I. TREATMENT PREFERENCE

What type of treatment - hospital dialysis, home dialysis, or transplantation - do you think is best for patients? Why?

If you were a patient, which treatment would you select for yourself?